

# Dealing With Cancer:

## A Personal Perspective

Advice for patients and loved ones from someone who has been both.

David Reichlinger



# Dealing With Cancer: A Personal Perspective

Advice for patients and loved ones  
from someone who has been both.

David Reichlinger

Copyright © 2025 by David Reichlinger

All rights reserved.

[davidreichlinger@gmail.com](mailto:davidreichlinger@gmail.com)

*To my darling Karen, members of the club and those  
who love them.*

# Acknowledgements

Many people contributed to this book. Those who complimented me on my blog helped me decide to write it. Those I met during treatment moved me with their stories. I have received encouragement from a number of people.

Natalie Niswander offered helpful advice on the final section. Sue Gongwer made sure I had my facts straight when writing about Karen. Special thanks to Laura Everts. She helped me make this a better book.

# Table of Contents

INTRODUCTION 7

SECTION ONE: LEARNING ABOUT CANCER 9

One – Cancer: The Basics 10

Two - Karen's Story 17

Three - My Story 21

SECTION TWO: DEALING WITH EMOTIONS 25

Four - The Initial Period 26

Five - Coming to Terms with Your Emotions 34

Six - Getting Help 43

SECTION THREE: LIVING WITH CANCER 49

Seven Your Cancer Self 50

Eight – Dealing with the Medical Establishment 54

Nine – Treatment 65

Ten– Dealing with Close Loved Ones 81

Eleven – Dealing with Other People 86

Twelve - Being a caregiver 91

Thirteen – Your Regular Life 95

SECTION FOUR: RECOVERY 105

Fourteen – Remission 106

SECTION FIVE: WHEN RECOVERY ISN'T POSSIBLE  
115

Fifteen – Facing Death 116

Sixteen – Saying Goodbye and Moving On 127

# Introduction: It's Up to Us

If you downloaded this book, either you or someone close to you has been diagnosed with cancer. I'm very sorry that you have joined our club.

A team of highly trained professionals is seeing to our medical needs. Living with cancer is a different matter. Even if we have a good support team, they aren't trained to help us. Most, if not all, don't really understand what we are going through. Dealing with cancer is up to us.

I have been in your shoes. I lost my girlfriend Karen to lung cancer and am in remission with treatable but incurable lymphoma.

My experiences have given me a purpose. Helping people like you is an important part of my life. I would love spending my time volunteering but the effects of cancer and other health issues make that impractical.

Instead, I went online and joined a number of Facebook cancer groups. I have replied to thousands of posts.

I wrote the first version of this book several years ago. My online experience plus research and analysis has allowed me to create a more comprehensive book. I realize it is unusual for a nonprofessional to write a book like this. It has certainly been a challenge. While I believe it will be useful, I encourage you to read others.

The book is divided into five sections. Section One gives some basic information on cancer and recounts Karen's and my stories.

Section Two covers the emotional aspect of cancer. Chapter Four discusses the time just after diagnosis. Chapter Five is about coming to terms with our emotions. Chapter Six talks about getting help.

Section Three deals with living with cancer. Chapter Seven is about being the person we want to be. Chapter Eight covers working with the healthcare system. Chapter Nine concerns receiving treatment.

Chapter Ten discusses the relationship between the patient and loved ones. Chapter Eleven is about dealing with the public. Chapter Twelve is dedicated to those incredible people who are caregivers. Chapter Thirteen relates to life outside of cancer.

Section Four is about remission. This is covered in Chapter Fourteen.

Although great strides have been made, some aren't able to recover. Chapter Fifteen discusses terminal cancer. Chapter Sixteen is about dealing with losing a loved one and the recovery process.

How you use the book is up to you. You can read the entire book or just the chapters that apply to you. Read it in the order that suits you.

This book has been a labor of love. I hope you will find it useful.



# Section One: Learning about Cancer

I thought I had a good understanding of cancer because of my experience with Karen. I realized how little I knew when I was diagnosed. Cancer is difficult to understand for someone who hasn't experienced it.

This section is designed to provide some background. Chapter One offers some basics on cancer.

We can also learn through the experience of others. Chapters Two and Three covers Karen's and my experience. One has a happy ending (at least so far) and one didn't. We both reacted with strength but in different ways.

# Chapter One: Cancer: The Basics

Cancer has always been with us. It was first described thousands of years ago in ancient Egypt. Hippocrates named it. He thought that a tumor with its blood vessels resembled a crab. That's why the disease and zodiac sign have the same name.

Our ancestors didn't worry much about cancer. Diseases such as smallpox, cholera and typhoid fever were far more deadly. The lack of modern technology made it harder to diagnose.

Once cancer was considered to be hopeless. New surgical techniques and treatments are constantly being developed.

Our attitude toward cancer hasn't necessarily kept up with the medical advances. The idea that cancer is an automatic death sentence hasn't been true for generations.

We may think of a cancer patient as someone with no hair who looks really sick. Most patients show no outward appearance of having cancer.

We need to redefine our idea of cancer. It is a family of diseases. Each one has its own characteristics. The treatment can vary significantly from one to the next. Sometimes surgery alone will suffice. Other treatments are often necessary.

We often view cancer as a one-time disease. That was true when few survived. Some cancers, mine included, are like a chronic disease that can flare up.

### **What is cancer?**

We usually think of a disease as an invasion by an outside agent like a virus or bacteria. Cancer is entirely different. It comes from changes in DNA during cell division.

Cell division is a natural, constantly occurring process. It is estimated that a person will experience around ten quadrillion (10,000,000,000,000,000) divisions over a lifetime.

Before a cell can divide, it must make a duplicate copy of its DNA. Sometimes there are errors in this process. New cells can be created with different DNA. This is called a mutation.

Cell mutation is how evolution works. We have gone from single cell organisms to the incredible complexity and diversity of life we have today. It is an ongoing process. For example, more babies are now born without wisdom teeth.

A portion of the genome controls the rate of growth and lifespan of cells. If it is altered, cells can grow much faster and live longer. Sometimes the immune system is able to kill them. Surviving cells can form a tumor. Benign tumors do not spread elsewhere. Those that have that capability are called malignant. That is the definition of cancer.

## **Types of cancer**

There are well over 100 different kinds of cancer. They can be broken down into two categories. Most are solid tumors that grow on tissue. They are named after the part of the body that is affected. A suffix is added to refer to the type of tumor. Most common are carcinoma, sarcoma and blastoma.

There are also malignancies that are in the bloodstream, lymph system or bone marrow; leukemia, lymphoma and multiple myeloma. They are sometimes called liquid tumors.

## **Warning sign**

Sometimes, as it was with me, there are no signs at all. It may take time for one to appear.

This is not a straightforward process. Many signs have multiple causes, often totally unrelated to cancer. We must not jump to conclusions.

Here are the most common signs:

1. Appetite loss
2. Blood in the stool or change in bowel habits
3. Difficulty urinating or blood in the urine
4. Persistent cough
5. Extreme fatigue
6. Persistent fever

7. Lump in the neck, under arm, groin or breast
8. Night sweats
9. Changes in the skin
10. Swollen lymph nodes
11. Trouble swallowing
12. Unexplained weight loss
13. Nausea and vomiting

Anyone with a warning sign should mention it to their physician.

## **Diagnosing**

The process begins when signs are present or a screening raises suspicion.

The first step is to have blood testing done. An abnormal reading may indicate the presence of cancer. Getting an MRI, CT or PET scan is then performed.

People may inherit a gene that increases the likelihood of certain cancers. Sometimes genetic testing may be done.

If something appears on the scan, a biopsy is necessary. It can be accomplished either with a needle or by surgery. Treatment cannot begin until the type of cancer has been diagnosed.

Doctors have several ways of describing the characteristics of a given cancer. The one we are most

familiar with is staging. This is a system for rating the degree the cancer has spread. They use a score of 0 to 4. Determining the aggressiveness of the tumor is also important.

## **Contributing Causes**

Although mutation is a normal process, there are a number of factors which can increase the possibility of cancer. They include:

1. Lifestyle – The easiest way to reduce the risk of cancer is to quit smoking. It is responsible for 80% of lung cancers and increases the likelihood of others. Alcohol, diet and obesity also play a role.
2. Occupational - Exposure to hazardous materials such as asbestos will increase the chance of getting cancer.
3. Radiation – Medical equipment and other sources such as radon have an effect. We must not let this concern keep us from getting vital tests. The danger of not being diagnosed far outweighs any radiation risk.
4. Disease - Certain viruses and bacteria can be a factor.
5. Genetics – People don't inherit cancer but they may inherit a mutation that can increase the likelihood of it.

## **Treatment**

Surgery was the first treatment to be developed. This would have been a harrowing experience before the days of anesthesia, sanitation and sophisticated medical knowledge. The development of imaging and new surgical techniques allows for much greater precision. For example, a lumpectomy is often done instead of a mastectomy.

Radiation therapy was the next treatment to be developed. Like surgery, it directly targets the tumor.

Chemotherapy uses drugs to destroy cancer cells. It targets fast growing cells. That is why some people lose their hair. Improvements are made by finding new drugs and new uses for existing ones.

Immunotherapy works by enhancing the ability of the immune system to fight cancer cells.

Other treatments are also used. For example, some cancers respond to hormone therapy.

## **Curing cancer?**

When people talk about curing cancer, often they mean getting rid of it entirely. We have been successful at eliminating diseases such as smallpox. by developing vaccines.

Curing cancer is far more complicated. It would involve curing many diseases, not just one. It also means interfering with the way cells mutate. Even if we could

develop the technology, I would be wary of using it. It effectively would mean replacing evolution.

There is still much that can be done. We will continue to develop new treatments and ways to detect cancer earlier. The most effective way of reducing cancer doesn't require any new science. We just have to live healthier.



## Chapter Two: Karen's Story

Note: Karen's strength has always inspired me. However, some may not want to read about a person who lost their battle with cancer.

My girlfriend Karen led an extremely hard life. She had serious health issues throughout her adulthood. She endured dozens of surgeries and countless hospital stays. She was widowed in her thirties and again in her fifties. Fortunately, she was an incredibly strong person.

During one of her hospital stays, doctors found a spot on her lung. She told me she thought it was a pneumonia scar.

One day we were out for lunch and stopped by the hospital for routine lab work. We were waiting for the valet to bring my car. She had a phone call. I walked a few steps away to give her some privacy. Then I heard her repeat the word carcinoma. It felt like the end of the world.

We had planned a cruise with some close friends. The first question she asked the oncologist was whether chemo and radiation could wait until we got back. Of course, the answer was no.

She was one of the most loving, caring people I ever met. We got the news just a few days before Christmas. She wanted to only tell her best friend so that the family would have a happy holiday.

She grew up as an only child and spent many years as a widow. She was most comfortable working through issues by herself. It took me awhile to realize it.

Being such a caring person, she felt the need to protect me. The only time the subject of her death came up was when she was worried about what would happen to her cat. I didn't need protecting but decided that letting her think she was doing so gave her comfort. I believe this was the right decision. I would have preferred that we openly discussed it but felt her needs should be given priority. Not talking about it made it harder for me.

I am oriented toward solving problems. There was absolutely nothing I could do. I have never felt so powerless in my entire life. I could run errands and try to support her but that was about it.

A PET scan showed that a lung and two lymph nodes were affected. Her health problems complicated treatment. Surgery would have been the best option but was out of the question. The oncologist had to use less powerful drugs. She had chemo once a week and radiation five times a week for seven weeks.

Karen had several side effects. Nausea was her biggest issue. That, combined with her other health problems, made her really miserable. The doctor said she would likely keep her hair but it didn't work out that way.

I don't know how she did it, but she was upbeat most of the time. Her best friend later told me she had a few meltdowns.

Her treatment finally ended. She slowly started to feel a little better.

She was strong enough for us to take a trip to Florida about six weeks later. We visited the friends we had planned to cruise with. Both of us thoroughly enjoyed it. It was the happiest week of my life.

The oncologist waited three months before ordering another PET scan. We were overjoyed when it showed she was cancer free.

Our happiness was very short lived. She very soon had a stroke (her third). The MRI showed a small tumor deep in her brain.

She bounced back and forth from the hospital to a nursing home. She wasn't sick enough to be hospitalized but managing her health issues was difficult for the nursing home to handle.

Everything she was going through affected her mentally. She so dearly loved her great-grandchildren. The day I had to explain to her who they were was almost as hard as losing her.

They gave her a high dose, precisely targeted radiation treatment. The doctor told us all it would accomplish was to slow the tumor's growth. I realized I was going to lose her. I'm sure her son and best friend reached the same conclusion but none of us said a word.

She began having more and more problems. She had more issues with confusion. There were hallucinations but I never witnessed them.

I visited her one day and she seemed like her old self again. I thought there might be a chance she would make it. Instead, she was going through a final surge that sometimes precedes death.

Two days later I got word she was slipping away. She was alert that morning. We were able to say our final goodbyes. At long last, her suffering was over.

They talk about acceptance as the last stage of grief. I reached it the day after she died. Dealing with my loss took a lot longer. There are still some tough moments.

Going through this with Karen was very hard. However, some of my favorite memories of her happened during this time.

We were together for only two years. She was the love of my life. It has been nine years since she passed away. I think of her every day. They usually are happy thoughts of our time together.

It took me about two years to come to terms with it. I was thinking about dating again but then I was diagnosed with cancer.

## Chapter Three: My Story

Like Karen, my cancer was discovered by accident. I contacted a spinal orthopedist after developing back pain. He said both hips needed to be replaced and ordered an MRI.

A nurse called to say they found something on the MRI. The possibility it was cancer certainly occurred to me. The doctor ordered a CT scan and referred me to a hematologist (a doctor specializing in lymphoma and leukemia).

I was prepared to hear the news. The doctor confirmed it was cancer, most likely a form of lymphoma. I was shaken but still keeping it together. That all changed when he told me the mass in my abdomen was the size of a volleyball. He showed me an image. All I could make out was my liver and the mass. The other abdominal organs had been squeezed enough to be unrecognizable.

I was totally stunned! It made absolutely no sense. I felt fine but had a giant tumor. He ordered a PET scan and a surgical biopsy.

While still reeling, I had to tell family and friends. I especially hated telling my elderly parents. My mother thought she would never see me again.

Unlike Karen, I processed the news by talking to people. Maybe if I told the story enough times, it would begin to make sense.

I desperately needed something to do. Since I enjoy writing, a blog made sense. I signed up with CaringBridge. They provide free blogs for those with serious medical issues.

My first thought was that it was a convenient way to keep people updated. I quickly decided to also discuss my emotions. Using it to clarify my thoughts and feelings was my therapy.

Getting the diagnosis was a surreal experience. Nothing seemed to make sense.

My math geek personality took over. I was sorting things out on a spreadsheet. The only certainty was being determined to fight it with every ounce of energy I possessed.

The biopsy indicated it was follicular lymphoma. The doctor gave me a mixture of good and bad news. The five-year survival rate looked promising and the tumor was slow growing. Although treatable, it is incurable. It had metastasized extensively. There were dozens of metastases in my abdomen and some elsewhere. That meant it was stage four. However, lymphoma at that stage is still treatable.

A combination of chemotherapy and immunotherapy was the only option. Since there was no standard treatment, I asked for a second opinion. The doctor arranged for an appointment with the leading lymphoma expert in the state. The first available time was a month away.

He recommended a different treatment with far fewer side effects. That sounded good to me! My doctor agreed. I had a trip planned. After thinking it over, I decided to cancel. I didn't want to delay treatment for even a single day. It was time to start fighting!

There would be six treatments spaced four weeks apart. I knew what to expect from taking Karen to her appointments. Inserting the IV was the only discomfort. Then it was a matter of sitting around waiting for the session to end

I enjoyed meeting other patients. Listening to them was inspirational. One lady had beat cancer five times and was on round six. Some were in stage four just trying to buy a little time. One of them was taking care of her husband. He also had cancer and was in the early stages of dementia.

The oncologist ordered a CT scan halfway through treatment. The results were encouraging. The mass had shrunk significantly, all the metastases were gone and none of the abdominal organs had been damaged.

He ordered a PET scan after the sixth session. I was thrilled to learn I was in remission! I went on maintenance treatment every eight weeks for two years. The doctor said I was doing so well that he cancelled it after six sessions.

Getting stage four lymphoma was really bad luck. Otherwise, I have had incredibly good fortune. My back pain is the only reason they found it. I had really good doctors. Now I'm in remission.

After treatment there was a serious problem with fatigue. It was already an issue since a benign pituitary tumor destroyed my pituitary gland and the brain's sleep center. The treatment made it much worse. This has had a tremendous impact on my day-to-day life.

Losing Karen and getting cancer have been hard. If I was destined for both, I am so glad it happened in that order. That wonderful lady would have worried herself half to death over me. I had hoped to find another relationship but fatigue has made dating impossible.

I come from a very long-lived family. That means I will likely have it return, possibly several times. I may or may not win the next battle but will give it all I've got.

I assume a favorable scan gives me at least a year. Then I decide what I want to accomplish in the next year and work on it each day. Whether I die the following year or live to 100, I will have had a good year. I call it a one-year lease on life with option to renew.

Many are suffering more than me. You may wonder how I can relate. I had a ringside seat to Karen's misery.



## Section Two: Dealing with Emotions

Cancer patients and loved ones experience sadness, fear, anger and many other emotions. Some try to cope by living in denial or take another unhealthy approach. Those around us likely don't understand what we are feeling. Sometimes we're not sure ourselves.

Chapter Four covers the initial period after diagnosis. Things will eventually settle down. The news is no longer a shock. Treatment is likely underway. It is then time to begin to come to terms with our emotions and find a path forward. This is discussed in Chapter Five.

No matter how strong we are, cancer is not a do-it-yourself project. Chapter Six deals with getting help.

## Chapter Four: The Initial Period

Cancer! It's impossible to describe the shock when a doctor uses that word. Our life is totally altered in an instant whether we are a patient or loved one.

Questions start popping up. We wonder about the treatment and how our life will change. The biggest question of all is about living or dying. Nobody has any answer at this point.

While we are still reeling, we need to tell those close to us. Passing this pain on to others makes it even worse.

This is all we can think about. However, we have to somehow keep our regular life going.

How we react is determined by our experiences, personality and whether we are the patient or loved one. My past challenges helped me cope. Losing Karen made cancer much more real.

We are in a world where nothing seems different but everything has changed. In the blog I described myself as feeling like a jigsaw puzzle in pieces on a table.

This initial shock happens to both patients and loved ones. Support is focused on patients as it should be. Loved ones may end up fending for themselves. That was the situation with me.

The object of this initial period is to accept the diagnosis as a fact. We can't begin to deal with our emotions until then.

In the horrible early days, it seems like we will never adjust. The time will come. The shock will ultimately begin to wear off. One day I thought I had reached it. I was a little premature but soon got there.

Here are some ideas to help get through the initial period.

### **Talk it out**

People like Karen are able to deal with this burden alone. The rest of us can really benefit by talking to others. They can give us support. Unless they have shared our experience or are a medical professional, they cannot give us understanding or advice.

People can react to hearing about cancer in unusual ways. They mean well but may say or do the wrong thing.

Ideally, you are able to find someone who has been through this. You may want to join a support group. I recommend that you get involved with social media cancer groups. There is an army of people out there ready to help.

### **Build your support team**

I was able to take care of myself. Even so, I had a huge support team. I knew an oncology nurse who was extremely helpful. A close friend took me to a couple of appointments and my first treatment. A cousin who had just been diagnosed was very supportive. Many people offered their support and a church prayed for me.

Some will need more help than me. Whatever your situation, you need to have a support team. We all need help at times and shouldn't be too proud to ask for it.

### **It's OK to feel the way you feel**

We are trying to get through this the best way we can. There are no rules on how to do it. We can cry or not cry. We can go out and have fun or stay home and be sad. As long as we don't harm ourselves or others, we can respond any way we like.

### **Take things a step at a time**

We need to focus on the next treatment, scan or appointment. None of us know what the future has in store for us. Worrying about what might happen twenty steps down the road accomplishes nothing.

### **Use your beliefs**

Many find comfort in their religious faith. What helped me was the belief I was strong enough to deal with whatever the future had in store for me. We need to find those beliefs that can help us cope.

### **Don't live in denial**

Sometimes it can be very difficult to see things as they are rather than as we wish they were. Living in denial can be dangerous. Lots of people die because they can't face reality.

## **Engage in physical activity**

Exercising or playing a sport is a good way to burn off stress. Just don't overdo it.

## **Find your pressure relief valve**

Many pieces of equipment have a pressure relief valve. It releases fluid or gas when the internal pressure gets too high. Otherwise, the system could explode.

We also need one. Each person has to find what works for them. It could be an enjoyable activity, completing an important task, time alone, time with others or something else. We need to avoid a psychological explosion.

My analytical brain saw cancer as a problem to be solved. It gave me a sense of accomplishment.

## **The Silver Rule**

Many of us are more comfortable helping others than receiving help. We should follow what I call the Silver Rule. Based on the Golden Rule, it says "Let others do unto you as you would do unto them." Allowing people to help lets them feel useful.

## **Pamper yourself**

Give yourself a special treat. I'm not suggesting buying a sports car or eating a gallon of ice cream in one sitting. Do something you really enjoy and might not do otherwise.

## **Stay away from Dr. Google**

It is natural to get on the internet and start reading. There is a lot of questionable information out there. We don't know enough yet for a search to be of help. It can be useful after we have a diagnosis and treatment plan.

## **Procrastination**

There is no way we can keep everything going plus cope with cancer. Some things need to be put off. That may go against our nature. We need to remember that fighting cancer is the top priority.

I never got around to writing a will. Trying to figure out what to do just after being diagnosed was more than I could handle. I took a couple of stopgap measures and quit thinking about it.

## **Understand that our self-worth is within us**

Some people define their worth by the role they play. It could be taking care of the family, their job, helping others, etc. Cancer may limit our ability to play that role. If it was the basis of our self-worth, we may feel valueless. We need to realize that our self-worth comes from who we are and not what we do.

## **Enduring the wait**

One of the real challenges of the initial period is enduring the wait to get news. This is certainly frustrating. Constantly thinking about it causes

tremendous stress. We need to find ways to distract ourselves.

### **Don't beat yourself up**

None of us are at our best when we are stressed. We make mistakes we normally wouldn't. That's to be expected.

Some people are too hard on themselves. They wouldn't think of calling anyone else lazy, stupid or worthless but will do it to themselves. Berating oneself accomplishes nothing.

### **Quiet time**

Spending time in prayer, meditation, visualization, etc. can be quite helpful. Find a peaceful place where you won't be disturbed.

### **Avoid the what ifs**

We all want to know about our future. At this point, we don't have enough information to even guess at what might happen. There nothing to gain by speculating about possible outcomes.

### **Avoid looking for reasons**

"Why me?" is a question many ask. We may think searching for an explanation will make us feel better. Things just happen. Astronaut John Glenn went on a perilous spaceflight without a scratch but hurt himself falling in his bathtub. Even if past behaviors increased the odds, it doesn't mean it caused the cancer.

## **Give up the illusion of control**

It is easy to assume that life will continue as it is currently. This can lead us to believe we are in control. Now we are facing something over which we have little control. We need to accept that we have never been in charge. This point was brought home to me when I was in a collision with a cement truck. It could have been much worse but I walked away with only cuts and bruises.

## **Don't think in terms of fairness**

I see many posts where people say it's unfair. Of course it is. It's unfair anytime someone is diagnosed. Fair and unfair don't really describe how the world works. Much of life is random. Some win the lottery and others get cancer. We need to play the hand we are dealt as best we can.

## **Don't take on everyone's burdens**

Airline pre-flight announcements say, in the event of a loss of cabin pressure, put your oxygen mask on first before helping your children. The same idea applies here. We want to do whatever we can for those we love but must take care of ourselves first. It puts us in a much better position to help them.

## **Postpone major decisions**

Now is not a good time to make big decisions. Besides being in emotional distress, there are too many unknowns regarding the future.



The good news is that the initial period will come to an end. That's when the real work begins. It is then time to start the healing process, both physically and emotionally.

# Chapter Five: Coming to Terms with Your Emotions

The initial shock may have worn off but it's still a very stressful time for both patients and loved ones.

We consciously and unconsciously seek ways to cope. The key is to find what helps us the most. Living in denial or using alcohol or drugs makes matters worse.

Coming to terms with our emotions does not mean trying to be happy all the time. That is unrealistic and unhealthy. We are experiencing real emotions and need to feel them. Instead, we should strive to manage them in a way that works best for us.

## Some Observations on Emotions

There are some certainties in life. The sun will come up in the morning. Two plus two equals four. Emotions are a different matter entirely. Even so, there are some observations we can make.

### **Emotions are unpredictable**

We can see the road ahead when driving. Emotions aren't like that. We cannot predict how we are going to feel.

### **Emotions are temporary**

When we are going through a rough time, it is easy to believe we will always feel that way. That's not how it

works. We will feel better. Positive emotions are also temporary.

### **Emotions can be complicated**

Dealing with cancer causes many different emotions. They can be hard to sort out. We may be reacting to past events and not realize it.

### **Emotions may or may not reflect reality**

Someone might feel their life is over after getting the diagnosis. Feeling that way after getting a B on a test is another matter.

To me, depression is a poorly named disease. Being depressed when something bad happens is perfectly normal. Someone suffering from depression might think, feel or act in a way totally out of proportion to the situation. If our reaction to cancer is too extreme, it might mean we have depression.

I have had it for much of my life. In dealing with losing Karen and having cancer, I worked to keep my real emotions separate from those that come from depression.

If you think you might have depression, please get help! I suffered from it for over twenty years before telling anyone. I didn't want people to think I was crazy. Now I am on medication. It has made a real difference. Please don't make the same mistake I did.

Like depression, anxiety is poorly named. We are all anxious at times like this. Anxiety is a crippling fear. If

you suspect you have it or other mental issues, please get help ASAP. We cannot fix this on our own.

## No Right Way to Feel

One of the most important ideas in this book is that there is no right way to feel. I believe cancer may be easier to handle if we have a positive attitude. It helped me. A couple of times it made me overoptimistic. What worked for me may not work for you.

The mind body connection is well established. Stress can affect the body in many ways. Some believe a positive attitude can improve cancer outcomes. I have read on the subject and personally don't think there is a connection. Whether or not there is one, the belief that we are hurting our chance of recovery by not being positive makes matters worse.

Those close to us may push us to feel positive. Cancer is hard enough without being pressured to experience a particular emotion. Remember they mean well and are struggling to cope just like you.

## Getting News

As I write this, I am about three weeks away from getting the results of my annual scan. There is no reason to suspect cancer has returned but I know I must be prepared for that possibility. I am not obsessing over it but it is on my mind.

Anyone is bound to be concerned about impending news. We should try to minimize the amount it

interferes with living our life. I understand that is easier said than done. However, worrying accomplishes nothing.

Sometimes we get news we don't want. This is like the experience we had during the initial period. You might want to reread Chapter Four.

## Those Who Have Lost Someone to Cancer

It is natural to feel that you or your loved one will suffer the same fate. The circumstances may be different. Karen had a more severe cancer and major health problems that limited treatment. We are seeing many advances in treatment. Even a few years can make quite a difference. We shouldn't assume that history will repeat itself.

## If You are Having a Bad Day

No matter how well we are doing, we all are going to experience some bad days. It may not feel like it, but this is actually a good thing. It means we are accepting our circumstances rather than living in denial.

It's perfectly natural to feel sad or fearful. We shouldn't try to suppress these emotions but don't want to let it get to the point where we are deep in despair. We should try not to let a bad day turn into a bad week.

## Three Step Plan for Dealing with Emotions

We all need to find ways to cope. Using personal experience, reading and a lot of thinking, I believe I have developed a method.

This involves a three-step process. First, we need to identify our emotions. Next, we must determine if what we are doing is working for us or not. Finally, we need to find a way to get to where we want to be.

Before going any further, there are several points to keep in mind:

1. I know this sounds simplistic. That's because it is. It's designed to help with basic emotional issues, not serious ones.
2. It may help to share this with a trusted family member or friend.
3. This is an ongoing process. New issues appear and old ones reappear.
4. If it's not working, try something else. If you think you need to see a professional, please do so.

## **Step One – Taking Stock**

It is difficult to deal with our emotions if we don't know what they are. "I feel bad" won't give us much to work with.

It helps to understand both the emotion and the reason for it. This process can still work even if we can't label the emotion. The clearer we can be, the better.

This can be difficult for some. Take a little time each day to take stock. Writing a journal can be a great help for many. Don't try to censor your words. Let feelings surface freely. Some may prefer to talk it out or take

another approach. What matters is that we find a way to sort out our feelings.

Here are some examples:

“I am afraid to die”

“I am angry because I (or a loved one) have cancer”

“I am worried about what this is doing to my family”

“Poor me, it’s just not fair!”

“What’s the use of doing anything if I might still die”

“I’m so worried about what might happen that I find it hard to focus on anything else”

“I am struggling as a caregiver”

“I can’t bear to watch my loved one go through this”

## **Step Two – How is it Working?**

Once we have taken stock, we can determine whether or not we are managing our feeling the way we want, given our current circumstances. This should be based on our opinion alone.

Some emotions can be useful in healing but it’s a matter of degree. We may be angry but it shouldn’t turn to rage. Sadness shouldn’t reach the point where we are totally consumed by it. Being positive can be overdone if we aren’t facing reality.

It's difficult to determine how other emotions can be useful at all. Examples include worry, self-pity, guilt and jealousy.

We also need to look at the circumstances surrounding the emotion. Whether they are helpful depends on the emotion, situation, intensity and duration.

### **Step Three – Find a Way to Get Where We Want to Be**

This is the hardest step of all. You are the only one who can develop the right approach. All I can do is share my experience. Even if you don't have all the answers, apply the ones you do have.

Sometimes something simple can make a big difference. One day I was doing a good job of feeling sorry for myself. Then I thought of Karen and all she had to face. I felt really ashamed.

Just because we are where we want to be, we can't assume that issues have been resolved. I was a week past what I thought was my last treatment and became upset when hearing that it would continue. Then I learned I was in remission and it was maintenance treatment.

I thought my reaction was because of my disappointment, having had little sleep the night before or the necessity of postponing some orthopedic work. It took a few days to realize this shattered the belief I was done with this round of cancer once the



initial treatment was over. Cancer fights dirty so we must guard against false expectations.

The Serenity Prayer has been very meaningful to me. Just three lines speak volumes. Here it is:

God, grant me the serenity to accept the things I cannot change,  
Courage to change the things I can,  
And wisdom to know the difference.

It says our focus needs to be on living our life and fighting cancer rather than worrying about the future.

I wasn't focusing enough on emotions at first. My inner Mr. Spock took over. Once I realized this, I took a break from all the reading and planning.

Talking to other cancer patients was very inspiring. The Leukemia and Lymphoma Society arranged for me to speak to a survivor. I've already discussed the people I met during treatment.

My blog was therapeutic. Telling people how I was feeling was as much for my benefit as theirs.

What worked for me might not work for you. We each need to find our own answers. Sometimes a little thoughtful analysis might provide real insight.

The most important thing is to keep our eyes and ears open. We never can tell what might inspire us. It could come from a television program, a small child, another cancer patient or any of a thousand other things.

Dealing with cancer is very hard. Making the effort to get where we want to be emotionally is definitely worth the effort. Good luck on your journey!

# Chapter Six: Getting Help from Others

John Donne wrote the line “no man is an island” four hundred years ago. The sentiment is as true today as it was then.

Our needs are magnified whether we are a patient or loved one. We must define them to get help. It is an ongoing process.

Most of us need help dealing with our emotions. Sometimes it’s a sympathetic ear or shoulder to cry on. We may want to talk openly and honestly about our fears. We may wish to feel normal or to talk with someone who has been through it.

Some of us require help even if we are on solid ground emotionally. We need people to take us to appointments and treatments. We often have everyday needs we can’t physically handle.

Loved ones are also going through a rough time. They face the same emotions along with a feeling of helplessness. They may assume additional responsibilities. Some are caregivers. That is discussed in Chapter Thirteen.

## Family and Friends

Most of us have a network of family and friends. They can provide considerable assistance. There are several factors we should keep in mind:

1. They are also having a difficult time. They may not have accepted the diagnosis yet.
2. Being a patient or loved one is a very challenging experience. However, they are not the same experience. Someone who has not faced your situation will have a hard time knowing what you are going through. I thought I knew what it was like to have cancer because of Karen. Once I was diagnosed, I realized how little I knew.
3. They want to help. Many patients do not want to be a burden. Helping others lets loved ones feel useful. Remember the Silver Rule and accept help graciously.
4. We must understand their capabilities – One friend was very helpful but was uncomfortable when I mentioned the possibility I might die. We should make sure they have the ability to help meet our needs.
5. We must know how they can help – It isn't appropriate to talk about our deepest feelings with a casual acquaintance. That conversation should be reserved for someone really close.
6. Friends don't keep score. Sometimes one person in a relationship may need more assistance than the other. Karen's best friend was extraordinarily helpful. It sometimes bothered Karen that she couldn't reciprocate. I would ask if she would have done the same thing if the

friend was the one who was sick. Karen would say “Of course!”. That is how a good relationship works.

If your experience is anything like mine, the response you receive from others will be quite gratifying. It can be easy to take people for granted until we really need them.

There are a few situations that might arise. Some might try to become overinvolved. Remember you are in charge and gently tell them to back off.

Others may offer questionable suggestions. A neighbor told me about some guy on the internet who was curing cancer with seaweed. Politely thank them for their “helpful” advice.

People can behave in unusual ways around cancer patients. They don’t know what to say. It can bring out their own fears. The wife of a good friend would barely speak to me while I was being treated. Try to be tolerant if they say or do the wrong thing.

## People with Shared Experiences

Ideally, you have someone in your circle of acquaintances who has had a similar experience. I knew a woman who lost her husband the year before Karen died. She could relate to me better than my other friends and family.

It doesn’t have to be anyone close. I hadn’t seen her for many years before we reconnected.

The people I met during treatment never complained. They kept fighting regardless of their circumstances. It was very moving.

We need to respect their privacy. Some may prefer to visit with a family member or stay glued to their phone. All we can do is offer a friendly greeting and see how they respond.

If you do strike up a conversation, keep it light at first. “Hi, what kind of cancer do you have?” is not a good icebreaker. Some may not be comfortable discussing their illness.

It may seem difficult to have such a conversation with a stranger. Barriers are easier to break when people have something in common.

Instead of a hit or miss approach, you may want to join a support group.

## Social Media

I belong to several Facebook cancer groups and reply to posts every day. You should be able to find a group for your type of cancer. There are also general support groups.

There are many caring people out there ready and willing to help. There are also a few people peddling their “miracle cures”. Pay them no mind.

## Cancer Service Organizations

Although better known for research and prevention, the American Cancer Society has a lot to offer. They have a 24/7 help line and can answer questions about diagnosis, treatment, side effects, health insurance, etc. They can provide information on local resources. The National Coalition of Cancer Survivors is also useful.

Disease specific organizations can provide considerable assistance. For example, the Leukemia and Lymphoma Society also has a help line. They offer many other services such as financial assistance and support groups.

Local organizations can be especially useful. One in my area offers an incredible array of services.

## Professional Help

If you are having trouble coping or think you might have depression, anxiety or other issues, don't hesitate to get help. If finances are a problem, cancer service organizations or other nonprofits may offer counseling at a reduced price.

If you are considering suicide, **get help immediately!!** You have no idea how much suffering you would cause those close to you if you took your life.

The only time I was ever rough on a Facebook cancer poster was when a woman said her family would be better off without her. I used some impolite language

and talked about losing Karen. Those who love you will **never** be better off without you.

Cancer is not a do-it-yourself project. Be sure to take advantage of the resources available to you.



# Section Three: Living with Cancer

Many of us lead busy, stressful lives. Now we or a loved one has cancer. As we begin to deal with our emotions, we can start deciding how to live with it.

Chapter Seven is about being the person you want to be. Chapter Eight discusses working with the medical establishment. Chapter Nine covers treatment.

Chapter Ten discusses the relationship between the patient and close loved ones. Chapter Eleven is about dealing with everyone else. Chapter Twelve relates to life outside of cancer. Chapter Thirteen is dedicated to those incredible people who are caregivers.

# Chapter Seven: Your Cancer Self

Dealing with our emotions is not an end in itself. It allows us to start thinking about how to manage the massive change we are going through.

It can be easy to get into a rut. Comedian Buddy Hackett defined Beverly Hills as a place where a guy sits by the swimming pool and then one day is seventy-five.

We often focus on the problems of the day rather than what is really important. Rabbi and author Harold Kushner said “Nobody on their deathbed ever said ‘I wish I spent more time in the office’”.

If there is one positive thing about this horrible situation, it’s the wakeup call to examine our lives and focus on what really matters. This chapter is about how we respond to our circumstances and work toward becoming the person we want to be.

## Seven Steps to Finding Your Cancer Self

Before getting into details, here are some factors to consider:

1. Getting where we want to be is an ongoing process.
2. We shouldn’t make changes during the initial period or at particularly stressful times. That is when coping with our situation has to be our main focus.

3. Everyone is different. We each need to find what works for us.
4. It may take time to decide on an approach. I was fortunate to quickly find what fit well with my personality. Others may need to think hard to determine what works best for them.

### **Step One: Decide how to live with cancer**

I thought of myself as a cancer warrior fighting it with ferocity. I did this because it helped me cope rather than out of the belief it would affect my outcome. Others may want to focus on leading as normal a life as possible, simplifying their lives, maximizing time with family and friends or taking another approach. We each need to find what works best for us.

### **Step Two – Find your assets**

Now is the time to dig deep and find those resources we can use to help us become our cancer self. You are the only one that can find your assets. All I can do is share mine. They were:

1. My analytical personality allowed me to see things logically rather than emotionally. It also made it harder for me to deal with my emotions.
2. I had the examples of Karen's and my parents' extraordinary strength. I mentioned before the many struggles she faced. Both parents had to deal with a lot. When they were still young, each one had to face the possibility of life in a wheelchair.

3. I'm pretty strong myself.
4. I've faced adversity, especially losing Karen and having a pituitary tumor.
5. I knew many fine people I could count on for support.
6. Several serious hobbies gave me something to focus on.

### **Step Three – Put your plan into effect**

Thinking about how to respond is one thing. Doing it is another. Our assets give us the power to implement our ideas.

### **Step Four – What to do if the plan isn't working**

There will be times when the plan can't be followed. I tried to remain strong but sometimes fell short.

The song *Pick Yourself Up* was written nearly ninety years ago but its message still applies. As it says, "pick yourself up, dust yourself off, and start all over again".

I was confident that being a cancer warrior was the right approach for me. If your approach isn't working, develop a new one.

### **Step Five – Look for ways to improve your life**

You may find a few silver linings in that dark disgusting cloud. Our experience with cancer may help us find ways that we can use to change our lives.

Like everyone else, I have no idea what the future has in store for me. The challenges I had faced have given

me the confidence that I could deal with any eventuality.

Even if it isn't life-threatening, cancer is a strong reminder that we are not going to live forever. We can use this knowledge to get more out of life.

Facing my mortality gave me the best thing that ever happened to me. My dad was an avid photographer. I spent a year sorting and Photoshopping his pictures. Every day I would see images of people who had died. That got me thinking. I decided finding someone to share my life with was my top priority. Eventually I met Karen.

Cancer might spur you on to achieve a life goal. I had a cancer scare years ago. I am a dedicated birder and had 492 life birds. If the news was bad, I planned to head to Southern California and get my 500<sup>th</sup> bird. Fortunately, the news was good. I achieved that goal in Florida several months later.

Cancer may give us the desire to improve ourselves. Now I am trying to cut down on TV and other time wasters and am exploring new interests. I am becoming more patient. Learning not to sweat the small stuff is making life easier with less mental wear and tear.

I also found a cause. Writing this book is part of it. Finding ways to help patients and loved ones is an important part of my life.

Our experiences may provide life lessons. Unlike dealing with emotions or finding your cancer self, receiving life lessons is a passive activity. We need to pay attention to what is going on around us.

I had a garage fire many years ago. As I was standing across the street watching them fight it, it occurred to me that it was just stuff. You can always get new stuff but people are irreplaceable. That proved to be an important life lesson.

### **Step Six – Make changes**

Be sure to start small. Every January I would see a number of new faces huffing and puffing while mall walking. Almost all of them would be gone by February. Change can be hard. Don't beat yourself up if things don't work out the first time.

These changes are making me a happier and better person. It sure would have been nice to have gained all this without getting cancer but that's not how life works.

### **Step 7 – Review**

Nothing is set in stone when dealing with cancer. If there is bad news, forget about making changes.

These changes may be too challenging. If so, put them off. Perhaps they aren't as important as you thought. Ignore them and find new ones.

Good luck finding your cancer self!

# Chapter Eight: Dealing with the Medical Establishment

Going to a cancer center can be scary. No matter how we are feeling, we need to be at the top of our game. We must be prepared.

## Doctor Appointments

Doctors make up a small percentage of the total staff, yet nothing happens without them. It is their responsibility to prescribe all treatments. Their time is very valuable and they have limited time with each patient.

Appointments are an important part of getting care. Both the doctor and the patient need to have questions answered. Any adjustments in treatment must be decided. It is vital that we pay close attention. It is easy for us to hear what we want to hear.

Some people try to live in denial. They seem to believe that they don't have cancer until a doctor tells them. This is a very dangerous delusion. By the time they finally see a doctor, it may be too late.

Here are some ideas to help you get the most out of your visit.

### **Bring a list of prescriptions**

You will need to complete a medical history form including a list of prescriptions.

## **Don't jump to conclusions**

It's very easy to assume we have cancer. Often, that's not the case. My mother had a mass that turned out to be a cyst. We must not jump to conclusions. It is easy to do. I have done so myself.

## **Take an active role in managing you care**

Patients used to do as they were told. Medical care today is a partnership. It is our responsibility to provide accurate information and express any concerns we may have. Their role is to make recommendations but we make the decisions.

## **Consider having someone manage the details**

It can be useful to have a person keep track of all the details and advocate on your behalf. Karen's best friend worked tirelessly to help her. I am convinced she extended Karen's life.

## **Be open and honest**

We need to tell the doctor what we are experiencing. Since we don't know what is important, we need to explain any problems we are having.

Some questions may be personal or embarrassing. It is vital to be open and honest. Missing or inaccurate information could possibly affect treatment.

## **Focus on reports and treatment**

Think of the appointment like a job interview. Other than the initial pleasantries, it is not a time to chat.



Time spent with the doctor is limited so we must stick to the business at hand.

### **Bring someone to take notes**

These visits can be very emotional. It is helpful to have someone with you to take notes. I made the mistake of going to my first appointment alone. I hardly remembered a thing once the doctor described the size of the tumor.

A note taker is useful even if emotions are under control. You can concentrate on what the doctor is saying and respond with new questions.

It is certainly possible to record the session with the medical staff's permission. However, I believe that notes will be more useful

### **Don't focus on bedside manner**

Finding a good doctor is the key. A warm bedside manner is nice but not necessary. My doctor was very matter of fact in telling me that I had cancer and was in remission. That didn't bother me a bit.

Many doctors need to be unemotional to protect themselves. They may have just told someone they are going to die. Obviously, we want them to focus on us, not the previous patient.

### **Prepare a list of questions**

Having a written list of questions is necessary for a successful appointment, especially early on. This is one place where you don't want to "wing it".

The questions will depend on your particular circumstances. Here are some you might ask:

What will be covered at this appointment?

What tests need to be done?

What do the test results show?

What is my diagnosis?

How confident are you in the diagnosis?

What stage is the cancer?

What are the treatment options?

How will other health issues affect treatment?

What treatments do you recommend?

What are the possible side effects?

What is the five-year survival rate?

How likely is the cancer to return?

Is there a clinical trial available?

Should genetic testing be done?

What precautions should I take?

Will I be able to keep working?

### **Accept uncertainty**

If we take our car in for repairs, a competent mechanic can usually explain the problem and fix it. The human body is infinitely more complicated. We need to accept

that there may be some uncertainty. I've seen posts from people blasting their doctor because they are not 100% certain about the diagnosis. We need to have reasonable expectations.

### **Know what you want the treatment to accomplish**

We would all like a quick, simple, total and complete cure. It just isn't possible for many of us. We must understand what the treatment is expected to accomplish.

Any thoughts we may have had before diagnosis don't apply. I knew a woman who nursed both her mother and stepmother through breast cancer. She said she would never go through chemo but changed her mind when she was diagnosed.

### **Use the nurse practitioner**

It often isn't necessary to see the doctor if treatment is going well and there are no reports to discuss. Nurse practitioners are highly trained and will contact the doctor if necessary. Seeing the doctor when you don't need to means someone else has to wait.

### **Make sure you understand the treatment plan**

This can be challenging since we may be unfamiliar with some of the medical terms and have limited time with the doctor. If there are questions that weren't answered during the appointment, call and ask to speak to a nurse.

## **Medical terms**

We can't expect to understand medical terminology. However, there are some common words that have a different medical meaning than we are used to.

If a test shows the presence of cancer, it is said to be positive. Normally positive is considered to be a good thing but not with cancer.

Incurable means the cancer can be treated but may come back. I use the term incurable but treatable to describe my lymphoma.

## **Consider keeping a notebook**

This can be a valuable tool, especially if there are numerous side effects.

## **Know the level of detail you want**

The world is divided into concept people and detail people. Concept people just want the big picture and get frustrated with too much information. Us detail people want to know everything.

## **If you are happy with the treatment, say so**

Doctors often hear complaints. They would appreciate being told you are happy with the treatment.

## **If you are unhappy with the treatment, say so**

It is important to speak up if you have concerns. There is no need to rant and rave. Just calmly explain what is bothering you.

Don't bring up a complaint that doesn't affect your treatment or health. Nobody told me maintenance chemo had been ordered. It caused me some confusion and concern. I never said anything to the doctor since we had more important issues to discuss than a bureaucratic snafu.

### **Don't be afraid of the doctor**

Doctors can be intimidating at times. Even if they have a difficult personality, don't let that affect you.

### **Don't ask about life expectancy**

We all want to know what will happen in the future. The biggest question of all is how much time we or a loved one have left. Unfortunately, life doesn't let us know what's up ahead.

Unless you or your loved one are near the end, I suggest not asking the question. There are so many variables that it makes it very difficult for a doctor to give an informed response. My grandmother had a massive heart attack. We were told she wasn't expected to live through the night. She died nearly twenty years later at age 101.

Instead, ask about the five-year survival rate. Remember statistics are about the group, not the individual. Moreover, they don't reflect recent improvements in treatment or how much the prognosis can vary from one patient to the next.

Hearing a guesstimate of life expectancy can put a date on the calendar. Counting down the days to when a

person thinks they will die could lead to a self-fulfilling prophecy.

## Learning more about your cancer

Our time with the doctor is short. We are bound to have more questions. As I said before, the best source of information is one of the cancer center's nurses. Don't hesitate to contact them.

Doing research after diagnosis and a treatment plan may be beneficial. I learned there was no standard treatment for my lymphoma so asked for a second opinion. As I mentioned before, some cancer organizations may have a helpline.

Books can become outdated since there are continual new advances. The internet can be very useful but we must stick to reputable sites. Use them to learn about the cancer, not to try to determine a prognosis. Here is a partial list:

National Cancer Institute

American Cancer Society

National Comprehensive Cancer Network

American Institute for Cancer Research

Cancer.Net

Mayo Clinic

## Deciding on Treatment

After getting a scan, biopsy and perhaps other tests, it is time to decide on a treatment plan. Determining the course of treatment has to be our decision. We must make sure that we have the necessary facts to make an informed decision. I see posts from people trying to decide before the results of the biopsy are known. We may want a second opinion.

Some people may be stronger than others but nobody is born a cancer warrior. We can't let fear keep us from getting treated. We also shouldn't decide to do any unnecessary treatment

## Second Opinion

Karen didn't get a second opinion since she had little choice in treatment. I got one because there were a number of treatment options.

Some might be concerned about upsetting the doctor. Your life is way more important than their feelings.

There are a number of reasons for wanting a second opinion. They include:

1. Confirm or determine the diagnosis – As I already stated, sometimes there is uncertainty involved.
2. Decide on a course of treatment - A second opinion can be useful if alternatives are available.

3. Consult with a specialist – Finding a lymphoma specialist was very helpful for me.

4. Looking for another doctor – Make sure you are doing it for the right reasons. Don't get a second opinion just because of their personality. It's a different story if you honestly feel you can't work with them or don't have confidence in them.

5. Some want to live in denial and go to doctor after doctor hoping one will say they don't have cancer. It delays treatment and could cost them their life.

6. The insurance company requires it

7. Exploring the possibility of clinical trials

I was very comfortable receiving treatment from my original doctor. It was far more convenient to be treated close to home. Sometimes it may not be available locally.

I hope this chapter helps you deal more effectively with the medical establishment.



# Chapter Nine: Treatment

Many of us have mixed emotions about treatment. We want to fight the cancer but fear what treatment might do to us.

This chapter is designed to provide some basic information. It should not be construed to offer any medical advice. As I have already said, I am not qualified to do so.

## Getting Ready for Treatment

We need to understand the treatment plan. There are two ways to get the information we need:

1. Ask questions - I met with an oncology nurse before it began. She was very helpful and had prepared a manual for me. Make sure your questions are answered.
2. Do your homework – Reading about your treatment can be time well spent. Make sure to only use trustworthy sources of information.

Dealing with emotions is important. You may want to reread Chapters Four and Five. Here are a few ideas to help you get ready.

### **It's OK to be scared**

Everything about cancer is scary. It's perfectly natural to feel fear. Those who aren't afraid could be deluding themselves. We need to find a way to move forward despite our fears. That's the definition of bravery.

## **Don't pay attention to horror stories**

Some people may want to tell you about horrible experiences they or someone they knew had during treatment. One person's experience says nothing about what you or your loved one will go through.

## **You won't have all the side effects**

The treatment that was originally proposed for me had a long list of side effects. I joked that the only thing I was sure of was that I wouldn't turn green or sprout wings.

Reading about side effects is scary. We have to remember that we won't get all of them.

## **You aren't alone**

Being a patient or loved one is a lonely experience. We are facing something we never imagined would happen to us. People around us likely can't relate to what we are going through.

This can make us feel very alone. As I have already said, talking to someone who has shared your experience is helpful.

## **Surgery**

The idea of someone opening us up and cutting on us sounds pretty scary. Our imagination can make it seem worse than it actually is. This is particularly true if we haven't had much experience with it. I was scared when

I had my first joint replacement. By the third one, I wasn't even nervous.

## **Cancer surgery today**

The surgeon will remove the tumor and perhaps some nearby lymph nodes. Sometimes the tumor doesn't have clean margins. This requires the removal of some adjoining tissue.

Although surgeons still use scalpels, they have other tools available such as lasers, cryosurgery and other new technologies. Surgeons can operate using robots that do the actual cutting.

Surgeries are often far less invasive than they used to be. Gall bladder removal was once major surgery requiring a week in the hospital. Using laparoscopic surgery, my 100-year-old father had his gall bladder removed.

The timing of the surgery depends on the nature of the cancer. It may be necessary to perform it soon. Sometimes it will be done following other treatments.

## **Asking questions**

It helps to be informed. Ask the surgeon to explain the operation. Here are some questions you may want to ask:

What are the possible risks? This may increase fear levels but remember that most of what they describe has a very low probability of actually happening.

Will you get all of the cancer?

How soon before I can resume normal activities?

How long will the surgery take?

How likely is it to be successful?

What happens if it doesn't work?

It also helps to talk to someone who has had surgeries. Karen and I visited some friends. The wife was about to have an operation. In Karen she had a resource who had been through dozens of surgeries. Instead of asking questions, she continued to talk about how scared she was (by the way, the surgery went fine).

There may be some tests beforehand to determine if you are a candidate for surgery. I had to have an EKG and physical exam before each joint replacement.

### **The operation**

You will have a set of instructions you need to follow beforehand. Examples include eating and drinking.

Once you arrive, the staff will prepare you. You will meet with the surgeon. The anesthesiologist will discuss what type of anesthesia you will receive.

### **After surgery**

After surgery, you will be in recovery. Many surgeries are now done on an outpatient basis. You will be sent home with instructions on how to care for your wound. You will also be given a list of possible complications. Don't hesitate to get help if you think you have a problem.

Some surgeries may permanently affect a person. That may seem like a high price to pay, but it beats the alternative. An aunt was diagnosed with colon cancer. Its location required a colostomy. Not having surgery would have meant several extremely painful months before she died. Having the surgery was an easy choice for her.

Sometimes doctors are able to lessen the impact. Examples include breast reconstruction and artificial limbs.

## Other Treatments

Medicine continues to develop more treatments to fight cancer. They are often done in conjunction with surgery.

### **Radiation**

The discovery of x-rays and radium gave people the idea that radiation might be useful in treating cancer. Initial efforts often relied on guesswork. Great strides have been made in the effectiveness of treatment and reduction of side effects.

Radiation does not immediately kill cancer cells. It damages their DNA. This slows down growth and can keep cells from dividing. Eventually this causes many cells to die.

Three methods are used to administer it. External radiation involves shooting a beam into the tumor. This is usually done by daily treatment for several weeks. With internal radiation, a radioactive substance

is put in or near the tumor. Systemic radiation uses a radioactive drug.

Ideally, radiation (and other treatments) will destroy the tumor. It may also be used to reduce or slow its growth. This can be done to make surgery easier or to extend the patient's life.

People worry about radiation causing another cancer. There is a very small risk but it is far outweighed by the benefits of treatment.

Here are some questions you may want to ask:

What is it designed to accomplish?

How do I prepare for it?

How long will it last?

Are there any restrictions I need to follow?

What side effects might I experience?

Will I be able to continue with my normal activities?

The main possible side effects are inflammation, scarring, fatigue and suppression of the bone marrow.

## **Chemotherapy**

Chemotherapy drugs have saved countless lives. Strangely, their history dates back to a chemical weapon, mustard gas. This led to the development of new chemicals. In 1947 Dr. Sidney Farber conducted a successful clinical trial on children with acute leukemia.

Chemotherapy (or chemo) drugs interfere with the process of cell replication. Since cancer cells form more rapidly, it can be a very effective treatment. Different drugs work in different ways. The presence or absence of side effects has nothing to do with whether or not the drug is working.

It can be delivered in different ways. Most common is through an IV. Some chemicals are too toxic to go through smaller veins. They are administered through a port. A port is a small disc under the skin. A catheter connects it to a large vein. Sometimes it taken in pill form.

Treatment day starts with a blood test followed by an appointment with the doctor or nurse practitioner. Then you sit there. To me, it was like a long, boring plane ride.

Unlike surgery and radiation, chemo does not target a particular part of the body. It attacks fast growing cells. The downside is that it can't distinguish between normal cells and cancer cells. This is why some people lose their hair. Fortunately, normal cells are more likely to recover.

Chemo is often used with other treatments. For example, it could shrink a tumor before surgery.

There are often side effects. They can vary from person to person and depend on the drug used. Fortunately, they are developing drugs with fewer side effects and better ways to manage them. Some of the most common are:

Fatigue

Hair loss

Diarrhea and/or constipation

Loss of appetite because food doesn't taste right

Nausea

Mental foggiess (Chemo brain)

Bruising or bleeding

Pain

Mouth or throat sores

Dealing with side effects is discussed later.

## **Immunotherapy**

Immunotherapy works by helping the immune system fight cancer. It is part of the biotechnology revolution.

They work in a number of ways The primary approaches are to increase the ability of the body to attack cancer cells or make them easier to find.

Immunotherapy is often given in conjunction with other treatments. While there can be side effects, they are generally not as severe as chemotherapy.

## **Hormone Therapy**

Hormone therapy is used to treat prostate and breast cancers that use hormones to grow. It works either by



stopping the body from producing them or changing how they act in the body.

## **Treatment day**

Here are some tips to help get through the day:

1. Bring someone along, if possible – Having a person with you can help allay your fears and pass the time.
2. Bring something to do – I spent much of the time on my phone. Take whatever keeps you occupied.
3. Talk to people – I’ve already discussed the benefits of talking to other patients.
4. Be patient – Oncology nurses are very busy. Unless it’s an emergency, give them some time to respond to your request.

## **Side effects**

Karen had more of a problem with side effects than me. Part of it was due to her health issues but it was primarily a matter of time. Had I gone through chemo then, I would have likely have had a similar experience.

It can be easier to handle them if you know what is possible. A person doesn’t want to learn hair loss can occur when hairs show up in the sink.

They can vary significantly depending on the treatment used. As I said, a long list can be intimidating but you won’t get them all.

Here are a few suggestions:

1. Keep your eyes on the prize - The treatment making you miserable is fighting your cancer.
2. Learn what you can do to help – Sometimes there are actions you can take to lessen the impact. For example, some dietary changes may decrease nausea.
3. Report any side effects –Your oncologist and their nurses don't know you are having a problem unless you call. Let them decide how to approach it.
4. Learn the pattern – Some are likely to occur at roughly the same time after treatment. This can help you know what to expect.
5. Managing pain – Be sure to report pain before it gets out of control. Make a note of the details such as location, intensity, type, etc. That allows you to accurately answer their questions.
6. Dealing with changes in appearance –Learn about products that can improve your appearance.

Losing hair can be upsetting, especially to women. I knew Karen was concerned about how I would react to her hair loss. If I said it didn't matter, she would think I was just being nice. Instead, I made a joke of it and told her I liked her hair and could now take it home with me. All

I cared about was her getting better. I assure you that your loved ones feel the same way.

There are many options including hair pieces, scarves, turbans, hats and caps. Some prefer to do nothing. Karen thought her wig was hot and scratchy. She used scarves and turbans. Choose whatever makes you feel the most comfortable.

## Clinical Trials

Medical science keeps developing new cancer treatments. It also finds new uses for existing drugs. For example, my chemotherapy drug was developing in 1963 in East Germany but had been used for my type of lymphoma not long before I was diagnosed.

Research can only accomplish so much. Eventually it is necessary to test the treatment on humans. It needs to be judged for its effectiveness and safety. This is known as a clinical trial.

They are done in three phases. Phase I is designed to test the safety of the treatment. A small group is given a low dosage. Following groups will be given progressively higher doses.

The focus of Phase II is to determine if the treatment works. Patients are given different amounts in order to determine which level is most effective.

Phase III determines whether it is more effective than current treatments. Patients are randomly

given the new or old treatment. Sometimes a placebo may be used.

Clinical trials have rigid guidelines on who can qualify. If you do, make sure to get all the information you can. Look at the pros and cons so you can make the best possible decision.

## Palliative Care

Palliative care has many of the same goals as hospice care but provides care throughout the course of the disease.

It is a relatively new medical specialty designed solely to increase the patient's comfort. Dealing with physical issues is an important part of it but it treats the whole person.

Most of us are more familiar with hospice than palliative care. That can lead to the erroneous belief that these services are only available only at the end of life.

## If the Treatment Doesn't Work

We all hope that the treatment will get rid of our cancer once and for all. The human body is incredibly complicated and cancer is a formidable foe.

Sometimes we get news we don't want. Although there isn't the shock of the initial diagnosis, it is still a blow. We will need time to adjust to our new reality. You may want to read Chapter Four again.

Often another treatment is available. Making the decision about a new treatment is never easy. We must get all the facts and make a rational decision. No matter how we are feeling, we need to be able to think clearly.

## Alternative Medicine

After Steve Jobs was diagnosed with pancreatic cancer, he spent nine months trying herbal remedies, acupuncture, special diets and other nontraditional treatments. He eventually had surgery but by then it was too late.

It can cost billions of dollars to develop a new drug. A huge team of scientists is employed. There are many clinical trials. Finally, there is a rigorous approval process before the drug comes to market.

To me, it makes sense to rely on a demanding scientific process rather than try something that has never been tested. I have nothing against alternative treatments. They can be useful for certain things. I have a strong gag reflex. My dentist uses acupuncture so they can work on me. Precisely targeting and killing a part of the body is a lot to ask from an herb or a needle.

Keep in mind the placebo effect. People can report amazing results but it is all in their head. I knew someone with macular degeneration who thought she could see better after acupuncture.

I'm not a doctor or scientist. There could be alternative treatments that might be helpful. Try them if your doctor approves but don't make the same mistake Steve Jobs did.

## Follow up care

What happens after remission depends on the nature of the cancer. Some may need an occasional appointment or none at all. If it is likely to return, more action is necessary. I have appointments every six months and get annual scans.

## Dealing with the Cost of Cancer

Healthcare is extremely expensive. Most of us don't see the whole picture since either our employer or the government picks up much of the tab.

I didn't need to worry about the cost of my cancer treatment since I am on Medicare and chose the most comprehensive supplement available. It was a different story with my pituitary tumor. I had cheap, high deductible coverage and had to pay over \$80,00 out of pocket.

Here are some guidelines:

### **Fighting cancer must be our top priority**

If there are ways to save money without compromising treatment, that's great. If at all possible, we should try not to let economic concerns affect the outcome. Remember the oncologist is focused on treating you rather than what it costs.

## **Use a family member or friend to gather information**

You may already have enough on your plate. If so, let someone else get the information together.

Medical bills need to be scrutinized. I was once billed several thousand dollars in error.

## **Try to have treatment in network**

Managed care organizations will negotiate lower prices from doctors, hospitals etc. They will pay less if you go outside the network. People may not like having such a restriction, but it results in lower premiums.

## **When treatment is denied**

Sometimes a particular treatment may be denied. It may not be deemed medically necessary, be considered experimental, etc. The decision can be appealed or another treatment may be used. While they make mistakes, they are subject to litigation and regulation so will rarely issue a denial unless they have good reason.

## **Know where you stand**

You should have an idea of how much it will cost and what will be covered. You may need to meet with a financial counselor. The cancer center or hospital may have someone you can use. Cancer service organizations may also be able to help.

## **Look for financial assistance**

Medical facilities and drug companies have programs to help those who cannot afford the treatment. It is important to cooperate with them and show your willingness to pay what you can. Cancer service organizations and other charities may be able to help you financially.

Getting treated can be a grueling experience. We need to do whatever we can to get the best possible outcome. I hope that this chapter has helped you.



# Chapter Ten: Dealing with Close Loved Ones

Being a cancer patient or loved one is incredibly stressful. However, they are different experiences. I thought I knew what cancer was all about after Karen was diagnosed but realized how little I knew when it was my turn.

It is easy for there to be misunderstanding. It took me awhile to realize Karen wanted to deal with this on her own. She kept telling me how sorry she was we couldn't go on the cruise. At that point, it meant nothing to me. All I cared about was her getting better.

A combination of high stress levels and difficulty understanding each other can lead to problems. Here are a few suggestions.

## **Recognize that you don't really understand what the other person is going through**

Few people realize that they don't understand what their loved one is experiencing. I certainly didn't. Being aware of it allows for improved communication.

It's just as important to recognize that they don't understand you. I see lots of posts from cancer patients complaining that their family and friends don't understand them. Of course they don't. We can't expect someone to relate to an experience they never had. Patients also have difficulty understanding loved ones.

## **Educate each other**

Those close to you may say something upsetting. It is much better explaining how you feel rather than getting angry. You may have to do this a few times but they should catch on.

We also need to ask them to educate us. That allows you to deal with them more effectively.

## **Be open and honest**

We need to be open and honest with each other. Not doing so makes effective communication even harder.

Having to tell a loved one you have cancer is incredibly difficult. I already mentioned telling my parents. We want to protect those we love but they need to know. I saw a post from a terminally ill woman who hadn't told her mother. It's far better to learn the news now than after the daughter is gone. We can't protect people from reality.

## **Talk to someone who has been there**

No matter how much we educate someone, they can never totally understand our experience. Find a person who has been there. If you don't know anyone, try social media cancer groups.

## **Don't overdo being strong for each other**

It can cut off communication. We need to create an environment in which each person is comfortable expressing their feelings. Karen had absolutely the best

intentions in being strong for me but it made it harder for me to cope.

### **Let them help you**

Allowing a loved one to assist you takes away some of the helplessness they feel. Even the smallest thing I could do for Karen made me feel useful.

### **Follow their lead**

If we can't recognize what a patient is going through, it makes sense to follow their lead. This doesn't work if someone is depressed, angry or uncommunicative.

### **Be yourself**

Sometimes a loved one may act like a parent, be overly positive or act in other unusual ways. The patient needs you to be yourself. Loved ones benefit if the patient acts as normally as possible.

### **Show loved ones you are a person, not just a patient**

Karen's second husband died of cancer. Their grandson was afraid of him because he didn't look like Grandpa. He was reassured once her husband started talking.

People may view us strictly as cancer patients. We need to show them that we are also the person they knew before cancer. Others need to know that if they are upset with us, they can express it without feeling guilty.

## **Involve loved ones in the process**

Anything associated with cancer is scary. Understanding what is happening can reduce fears. For example, it helps if they know that chemo is really just a bunch of people sitting around with IVs.

## **Social life**

One challenge many couples face is maintaining a social life. The one who is sick may not be physically able to do much socializing. It's not fair to expect the healthy partner to always stay home. Discuss this and try to arrive at a compromise.

## **Allow patients to be themselves**

Having cancer is hard enough. Putting on a false front of positivity makes things even more difficult. It shuts off their ability to discuss how they are feeling. Make sure they are comfortable being themselves around you.

## **Let loved ones know how you are feeling**

Usually when people ask "How are you?", they are merely following a social convention. People who care about you really want to know.

We can put on any face we want to the world at large. Those close to us should know what is going on so they can respond accordingly.

## **Be a good listener**

Many of us are poor listeners. We are often thinking about what we are going to say rather than paying close attention. Here are a few ideas for becoming a better listener:

1. Let them talk – It's human nature to interrupt. Wait until they are finished.
2. Focus on what they are saying – Give them your complete attention.
3. Notice their body language and tone of their voice - We are missing part of the message if we just hear the words.
4. Try to determine their feelings – Being able to understand what feelings they are experiencing lets you communicate more effectively.
5. Show them you are listening – Nodding your head or saying a word or two lets them know you are paying attention.
6. Hold off on offering advice – Many jump in with unsolicited advice. Think carefully before giving it.
7. Restate what they said - This lets them know you understand them.

## **Don't be afraid to discuss difficult subjects**

Unfortunately, some cancer patients face a challenging future. Be willing to talk about it. You may have to wait until each person is ready to handle it.

## **Dealing with change**

Whether gradual or not, cancer brings about many changes. The patient may find they are unable to do things that used to be easy. The patient or loved one may be changing as a person. Let each other know what is happening.

## **Don't give people false hope**

We want to do whatever we can to protect those we love. However, we shouldn't give them false hope. If they are told everything will be fine and it doesn't come to pass, their pain will be greater and they may never forgive you.

Some try to protect children. Kids can tell when something is wrong. It is important to be honest with them. What they are told depends on their age.

## **Live your life but don't take undue risk**

As patients, we want to do as much as we can. Loved ones want to keep us safe. This can lead to conflicts over whether or not a particular activity is dangerous. Good communication is key to resolving these disputes.

This is a trying time for everyone involved. It strengthens some relationships and damages others. I hope this chapter has been helpful.

# Chapter Eleven: Dealing with Other People

People's feelings about cancer may cause them to avoid us. They may not know what to say or are uncomfortable being around us because of their fear of cancer. A few may be so afraid of losing us that they stay away. Some may even unconsciously think that they might catch cancer from us. There is such a stigma about cancer that people may act irrationally. The wife of a close friend would barely speak to me while I was being treated.

Others might not be pleasant to be around. They may complain about trifling matters or have a negative attitude. Some may pity you. That happened to me. It's fine to express concern but pity is condescending.

## Who to Tell

This is a personal decision. Usually, those closest to us need to know. Your employer should be told if you will be missing work.

Some want the world to know as little as possible. Others have no problem informing everyone. Telling people helped me cope. Karen preferred to limit the number of people she told. Do whatever is most comfortable for you.

## When to Tell Them

Anyone who knows when you are meeting the doctor should be told as quickly as possible. They are anxiously awaiting to hear from you.

The nature of your cancer can be a factor. I was part of a group of friends that met for breakfast every Saturday. One of them said she couldn't make it one day. She had a malignant tumor removed and needed no further treatment. She told us after the surgery.

Sometimes there may be a special occasion coming up and you want to wait. I already mentioned that Karen was diagnosed just before Christmas.

## What to Tell Them

I believe it is important to be honest. That still leaves a lot of latitude on what to say. I never told my parents I was stage four. Since lymphoma is still quite treatable at that stage, there was nothing to gain by telling them.

The same thing applies to feelings. I was concerned about dying, particularly in the beginning. I tried to express those fears to those I believed could handle hearing me talk about it.

If you choose to go public, tell as much or as little as you want as long as it's accurate.

It can be tiring to repeat your story over and over. A blog is an effective way to keep people updated.



CaringBridge is an organization that lets those with serious health issues set one up. It is very easy and will take just a few minutes.

## **Communicating with Others**

Whether you are the patient or a loved one, you will be dealing with others aware of your situation. They are concerned about you but may have trouble communicating effectively.

Here are some ideas to make things easier.

### **Try to be patient**

It can be hard, but we should try to be patient with others. To be perfectly honest, I didn't always practice what I preach. Once someone was going on and on about how her week was ruined because of ants in her kitchen. I held my tongue for a while but eventually suggested that cancer was worse than ants.

### **Ignore the parrots**

Parrots can be trained to talk but obviously they don't think about what they say. I remember reading a post from a woman who was extremely angry when someone told her not to get her hopes up. When somebody makes an idiotic remark, think of them as a parrot.

I read a post from a woman who was really upset when a relative told someone she had cancer. She

was still steaming after six months. We have more important things to be concerned about.

### **Dealing with difficult people**

Unlike those who make thoughtless remarks, some people can be negative, unpleasant or downright nasty. We already have enough to handle. We shouldn't have to put up with people like that. Some may change if we say something to them. If not, we should be around them as little as possible.

People can be a great comfort at times like this. We can't let their occasional careless behavior keep us from focusing on fighting cancer and living our lives.

# Chapter Twelve: Your Regular Life

Getting the diagnosis changes everything. Experiencing symptoms or side effects makes matters even more complicated. The same is true for loved ones, especially if they are a caregiver.

In spite of the challenges, we must strive to lead as full a life as possible. We can't let cancer take over our lives. We all need to decide how to fit our regular life into our new circumstances. Doing so takes time and effort but it is well worth it.

Making the adjustment was easier for Karen and me than it will be for many. Both of us were retired. We already had made accommodations to our lives due to health issues.

Each person needs to develop an approach that works for them. You may reach a few conclusions early on. It's likely ideas will come to you as you face the day-to-day existence of your new reality.

## Putting it all together

We need to revise the plan once we see what works and what doesn't. Dealing with cancer may also require modifications. Below are a few suggestions:

### **Take care of your health**

It is important not to ignore other health issues. Eating well and exercising have a number of benefits. Nausea

and other side effects can impact your diet. You may want to work with an oncology dietician. Make sure that any health issues are properly managed.

## **Redefine your priorities**

Almost everyone needs to redefine their priorities. Some things must be done. Meals need to be prepared and you have to go to work if physically able. There may be some things that now seem less important.

## **Urgent vs. important**

Author Stephen Covey talks about demands on our time that are a combination of urgent and important. It is very easy to constantly operate in crisis mode. Vital things, like raising children, may not get the attention they deserve.

A person can become overwhelmed if their focus isn't on what really matters. Once one of my staff came to me saying I needed to hire a person to help him. He prioritized his tasks. There must have been twenty-five priority A items. We sorted it down to eight. It turned out that he could take a positive step on each one over the next few hours.

## **Put some joy in your life**

Proverbs 17:22 says "A merry heart doeth good like a medicine: but a broken spirit drieth the bones". Some have claimed a relationship between laughter and healing. The important thing is that it makes us feel better in the moment. It also tells those around us that we are coping.

Cancer may take a lot from us; even our lives. We can't let it take the joy of living. Just do whatever puts a smile on your face.

### **Enjoy the people in your life**

People want to support you. As I have already stated, they may not know what to say or do. We need to overlook their occasional missteps and enjoy the pleasure of their company. It's a different matter if they are unpleasant to be around.

### **Find ways to pursue your interests**

I am a passionate birder but vision and mobility problems forced me to change how I go about it. I have become an expert at birding by ear and do much of it from my car.

Your health may not allow you to pursue your interests as you once did. Try to find a way to still participate. For example, you may love the outdoors but are not able to hike or camp. You can still go for a nice drive. If nothing else, you can read about your hobby.

You might also find new interests. Much to my surprise, I discovered I love writing almost as much as birding.

### **Keep active**

Many of us have to accept that we aren't able to do what we used to. It doesn't mean giving up. We should strive to do as much as we can. Many have limited energy. We need to use it effectively. Sometimes there may be a

special event that is worth expending all the energy we have.

### **Have some down time**

Time spent watching television or keeping up with social media may seem a waste. Anyone who is fighting cancer or is a loved one needs down time. Whether it is reading a trashy novel or watching sitcoms, take the time to relax.

### **Consider giving back**

We all remember the horrible shock of the initial diagnosis. We have learned a lot since then. Giving back is very rewarding.

You can volunteer at a cancer organization or reply to posts on social media. Helping others is a huge responsibility. We should only reply if we are confident we can help. Even though I have replied to thousands of posts, they are a small fraction of what I have seen.

### **Make sure the glass is half full**

Many of us have experienced a dramatic change in our lives. Our focus should be on what we still can do. Thinking about our limitations accomplishes nothing except make us feel sad.

Our object should be to have as happy and meaningful a life as possible. It doesn't happen automatically. We need to work at it.

# Chapter Thirteen: Being a Caregiver

Caregivers are the unsung heroes in the battle against cancer. They have many responsibilities. They need to keep going no matter how they feel. The patient may not always cooperate. On top of everything else, they are dealing emotionally with someone they love being seriously ill.

The word caregiver may bring up the image of someone providing substantial care to a person living with them. This is often the case. My definition is anyone who is devoting a significant amount of time helping a patient.

I certainly did everything I could for Karen but wouldn't consider myself a caregiver. I have had plenty of opportunity to observe them, especially my mom. I have also done research on the subject.

Several organizations have put together a caregiver's bill of rights. You may want to check it out.

Being a caregiver is a challenge under any circumstances. Here are some suggestions that may make the burden a little easier.

## Managing it all

It is easy to become overwhelmed. A little bit of management may make it seem more doable.

## **Getting organized**

Ronald Reagan once said “It’s hard, when you are up to your armpits in alligators, to remember you came here to drain the swamp”. I’m sure many caregivers feel that way.

Nobody can tell you how to get organized. Find an approach that works for you.

If you are acting as a medical advocate for your loved one, you need to have the information close at hand. This includes appointments, a list of medications and anything else that might be necessary.

## **Prioritizing**

Some may think they can do it all but that just doesn’t work. It is necessary to let some things go. In Chapter Twelve, I talked about urgent vs. important tasks. It’s OK if the house is a little messy or you serve simple meals.

One thing to let go of is perfectionism. There is no way to maintain impossibly high standards.

One thing not to ignore is taking care of yourself. More on that later.

Each caregiver will have their own priorities. Anything affecting the patient’s health has to be at the top of the list.



## **Try to make things as normal as possible**

I don't need to tell you how much life has changed for you and your family. Cancer shouldn't completely take over everyone's lives. Try to find ways for each person to have a life that bears at least some resemblance to what they had before.

## **Take things a day at a time**

Many people are overwhelmed at the thought of being a caregiver. Some try to anticipate everything that can possibly happen. That is like parents worrying about their newborn's college education.

We need to think of this as a series of sprints, not a marathon. Focus on what needs to be accomplished today.

## **Be flexible**

Some people are set in their ways. Trying to be that way while being a caregiver is a bad idea. For example, the patient's appearance may be important to you but doesn't matter if they are not seeing anyone that day.

The object of caregiving is not to work hard until you drop. It's to complete all the important tasks with as little wear and tear on yourself as possible.

## **Be ready for change**

One of the challenges of being a caregiver is changes in the patient's needs. They may experience good days and bad days. Their needs may change as the disease

progresses. We can't anticipate them so must be able to adapt.

### **Have reasonable expectations**

Expecting everything to go smoothly is a good way to set yourself up for disappointment. There will be problems. You must try to have reasonable expectations.

### **Take care of yourself**

People can lose sight of their own needs when caring for another person. Taking care of yourself not only benefits you, it makes you a better caregiver.

### **Manage your health**

It's easy for someone to be so focused on the patient that they aren't paying attention to their own health. Continue to eat right and exercise. Getting enough sleep may be a challenge. Make sure that any health issues are addressed.

### **Breathe**

Pause for a moment to gather your thoughts. Think about what to do next.

### **Find a way to vent**

I live a long distance from my mom so there was little I could do to help her take care of my dad. One way I could help was to allow her to vent her frustrations. Find someone who can do the same for you.

## **Get out of the house**

Being stuck in the house can become frustrating. Try to find ways to get out even if it is for a short time.

## **Treat yourself**

Being a caregiver should not mean putting your life totally on hold. Find ways to treat yourself. My mom really enjoyed doing crossword puzzles.

## **Dealing with guilt**

There are a number of ways guilt can creep up. You may feel you aren't doing enough or are taking a little time for yourself. You may also feel guilty that they are sick and you are healthy. All these feelings do is to make it harder to do your job.

We often feel guilty over things over which we have no control. Karen would apologize if her health didn't allow us to go out. She didn't owe me an apology since she did nothing wrong.

We all make mistakes. We should make amends and let it go. Guilt doesn't help anyone.

## **Talk to other caregivers**

A lot of people are caregivers. It helps to talk to each other. It doesn't need to be a formal group. It can even be online.

## Get help

No matter how dedicated, a caregiver can't do it all. They need help from others. This is not a sign of weakness. It's an act of love for a person wanting the best for the patient.

## **Don't be afraid to ask for help**

Cancer makes people feel helpless. Being useful is rewarding. That won't happen if you don't ask.

## **Seek input**

I have seen situations in which a person, acting out of the best intentions, assume they are the only one who knows what's best for the patient. In one case, a family member was ignored even though they had professional experience.

This approach makes people less willing to help. They will participate more readily if you seek their input.

## **Assign particular tasks**

Most people want to help but don't know how they can do so. They need a little guidance.

## **Fit the task to the person**

Someone might be uncomfortable taking care of the patient but would gladly mow the lawn. Make sure to fit the task to the person.

## **Have reasonable expectations**

Some are willing to pitch in and do whatever they can. Others may not be of much help. It's important to have reasonable expectations.

## **Some people will refuse to help**

I see Facebook posts from people who are extremely upset when a family member won't help. Of course that's unfair. It's fine to be unhappy with them. Getting really angry can distract from your efforts as a caregiver.

## **Consider hiring help**

Sometimes hiring help can make a lot of difference. My mom had someone come to watch my dad for several hours a week. You may need to consider someone with medical training. Bringing in an outsider can ease your burden.

## **The Caregiver-Patient Relationship**

### **Explain how you are feeling**

Some assume that the patient knows how you are feeling. That is an unwise assumption. You need to let them know what is going on.

### **Ask the patient how they are feeling**

Learning how the patient is feeling can help you understand each other and improve communication. Don't push it if they get angry or won't talk.

## **Don't always be in caregiver mode**

The caregiver is often in a position of power. That makes it vital that you keep the relationship you had before cancer. Otherwise, it can be more like a parent and child. Try to spend time each day outside of caregiver mode.

## **Help them maintain their dignity**

There are many ways cancer robs people of their dignity. Do what you can to help them keep some of it.

## **Dealing with anger**

This is one of the greatest challenges of being a caregiver. Anyone diagnosed with cancer is bound to be angry at times. They may have anxiety, depression, mental confusion or other mental issues.

When he was lucid, my dad told my mom how much he loved her and how lucky he was to have her. I also heard him shout and swear at her, call her horrible names and threaten to hit her.

Every situation is different so you need to decide how to respond. I think it is fair to expect some anger. The caregiver is a convenient target. However, there is a limit on how much you should have to endure. Most important is to never put yourself in a situation in which you could be physically harmed.

## How patients can help the caregiver

Being a caregiver is very stressful and demanding. Patients should do what they can to help them.

### **Show them your appreciation**

Clearly, you are going through a horrible situation. So are they. Make sure to show your appreciation. Thanking them is a good start. Find other ways such as flowers, special gifts, etc.

### **Apologize if you mistreated them**

It is easy to take frustrations out on them but they don't deserve it. Make sure you give them a sincere apology.

### **Get them some help**

Make an effort to get them some help. It can make a big difference.

### **Do what you can yourself**

When a person is feeling miserable, the idea of someone pampering them might sound appealing. However, it isn't fair to the caregiver. Make sure to do what you can yourself.

### **Make sure they still have a life**

Some caregivers feel guilty if they take time for themselves. They should still be able to go out and have fun even if you can't join them. Encourage them to do so.

## When being a caregiver is no longer possible

Being a caregiver is an act of love. However, the time may come when it is no longer possible. Sometimes the patient requires a level of care that only a group of skilled professionals can provide.

A change may be necessary for the caregiver's health or safety. My grandmother had extremely high blood pressure. There was no way she could continue to care for my grandfather.

Ideally, plans are made ahead of time. There can be a waiting period until there is a vacancy. The patient may resist. Be strong and do what you know is right.

I wish you all the best on this challenging journey. Hopefully this chapter has been of use.



## Section Four: Recovery

I used to think love was the most beautiful word in the English language. Then I thought it was benign. Now I think it's remission. This is discussed in Chapter Fourteen.

## Chapter Fourteen: Remission

It's very hard to describe the reaction to hearing a doctor say you are in remission. In that moment of ecstasy, it may seem like life will be smooth sailing ahead.

Any big change, even a positive one, has a period of adjustment. Early in my career I had to take a series of professional exams. Needing to study meant foregoing many pleasurable activities. Once they were completed, I put all that time into work. Eventually I wised up and led a more balanced life.

Some may have more trouble adjusting. Cancer can leave people with depression, PTSD or other mental issues. It may also lead to substance abuse. We cannot fix this on our own. My dad was in his eighties when he was treated for PTSD from his war experiences sixty years prior.

There can be physical issues. Many have to deal with the results of surgery or side effects. Side effects can have a profound impact on our lives.

This chapter also applies to loved ones. It's just as important that they make the adjustment. There is no way to get on with life for someone who obsessively worries. Caregivers are bound to be resented if they try to stay in that role.

There are several ideas to keep in mind as we move into the next phase of our life.

1. We have been through a lot and can't expect to react as if nothing has happened.
2. We should recognize that cancer has likely changed us as people.
3. Since we have changed, we can't expect to resume life as it was before. We need to find a new normal.
4. We have been granted the opportunity to get on with our lives and should make the most of it.

## Dealing with Emotions

### **Managing guilt**

Some may feel guilty they survived and others didn't. If anyone should have survivor's guilt, it should be me. Karen died and I lived. We should never feel guilty about something that is beyond our control.

### **Dealing with the possibility cancer returns**

Our biggest question is whether or not the cancer will return. Some are unlikely to recur while others are more likely. We all want to know about our future. Unless someone invents a time machine, it will be necessary to wait and see.

The future holds infinite possibilities both good and bad. It is a shame to spend our life worrying about one of those possibilities. Remission is a time to enjoy life. That's not possible when one is always fearful. All we are given is today. Living it with worry is such a waste.

## **Talk to someone in remission about your feelings.**

It is likely that those around us will still have a hard time understanding what we are going through. Just because we are in remission doesn't mean we are feeling fine. It helps to talk to someone who has been there.

## **Making the adjustment**

Making the adjustment is not easy. Here are some ideas to consider:

1. Remember you are much better off than a lot of other people.
2. Reread Chapter Four and apply it to your current situation.
3. Look for your assets. This concept was discussed in Chapter Five.
4. If nothing else works, seek professional help.

## **Getting a scan**

Everyone is bound to be nervous when it is time for a scan. All we can do is put one foot in front of the other and keep going.

## **Managing the physical impact of cancer**

Some have had their lives seriously altered by amputation, colostomy or other surgical procedures.

There can be sexual or fertility issues. Many don't have the energy they did before. Side effects may continue.

There are no easy answers. Pining for our old life just makes us more miserable. We need to make sure we have done whatever possible medically to improve matters. After that, we need to lead as rich a life as possible.

My chemo dramatically added to the fatigue issues I already had. I make an effort every day to do something important (like working on this book). If I am feeling better, I push to get the most out of the day. After that, it's just a matter of accepting the situation.

## If Cancer Returns

My doctor told me he doubts I will go ten years without it returning. It won't make it any easier when it happens. Nobody can prepare for the news ahead of time. Getting the diagnosis will certainly be distressing.

Here are a few thoughts:

1. Our past experience has made us stronger.
2. If we have a cancer likely to return, we are getting regular scans. That means it will be discovered earlier.
3. Improved treatment likely will be available. My doctor has told me about some of the advances since I was treated.
4. We still need an initial period to adjust.

5. Knowing those who were most helpful last time lets us reestablish our cancer network quickly.

6. We have a much better idea of what to expect.

We have been given a new lease on life. We need to make the most of it no matter what the future has in store for us.

## Dealing with Other People

**Your partner** - As wonderful as it is to be in remission, it can put pressure on a relationship. Some might be stuck in cancer mode or obsessively worried about it returning. Others may want to go back to life exactly as it was before. It's easy to make poor choices like I did after finishing my exams.

We might have changed in ways the other person may not have expected. The partner might be overprotective or not realize we aren't completely healthy.

Here are some ideas that might help:

1. Talk to each other. Nothing beats good honest communication.

2. Live for today. Don't be stuck in the past or be overly focused on the future.

3. This is not a time for major life changes.

**Family and friends** – Some of the same issues apply. Many people have out-of-date ideas about what cancer and remission are like. I certainly did.

They likely called and visited more while we were sick. Don't be surprised if they revert to old habits.

Some people may think of you as still being sick. They mean well but don't realize we want to be treated like everyone else.

I used to walk with a cane. Having a free hand meant I could easily open a door. If someone held one for me, I thanked them and moved on. It's easy to ignore special treatment from strangers. If someone close to you is doing it, have a talk with them.

## Workplace Issues

You might run into problems on the job. Some may think you aren't capable of doing it anymore. Others may treat you as if you still have cancer. You have to walk a fine line between getting what you need and not risking your job.

Here are some ideas:

1. Show that you can do the job – Actions speak louder than words. There is no need to make a big deal out of it. Just go about your business quietly and efficiently.
2. Seek accommodation, not special privileges – You might need some adjustments to do your job but make sure you aren't asking for a special benefit. For example, you may require a rest break but should then make up the time.

3. Pick your battles – What matters most is staying employed. Complaining about petty annoyances is counterproductive.
4. Don't overdo it – There is no point working yourself to exhaustion. Remember the story of the tortoise and the hare.

## Other Health Issues

Cancer has taught us how precious life can be. Now is a good time to address issues that can improve our health. Each person needs to find what works for them. If I go on a diet, I soon gain the weight back. My focus is on changing my eating habits. Start slow. It's impossible to make up for decades of bad habits in a short time.

## Leading a More Fulfilling Life

My dad told the story of a group of elderly friends. Several died in a relatively short time. They gathered at a church after the latest funeral. One man wondered aloud who would be next. He died a few hours later.

It is very easy to live life as if we are going to live forever. Cancer is a reminder of how precious each day is. We can use it to lead a more meaningful life.

Here are a few ideas:

1. Cut back on TV and phone time – Personal electronics have had a profound impact on our



lives but can take over. Cutting back on them gives us time for other activities.

- 2 Increase the quantity and quality of time spent with people – The support I received was a reminder of how important they are to me. Cancer has been our top priority. Now we can put people first.
- 3 Focus on your interests – Cancer limited our ability to pursue them. Now we can get back to them. The effects of cancer may require us to make adjustments.
- 4 Find a new interest – Finding a new interest can add a lot of satisfaction to life.

My initial experience with writing was doing English papers. That is no fun for a math geek. One of my grandmothers had written about her life. After she died, I planned to put her writings together with a little added commentary. It turned into a 250-page book and a passion for writing.

Maybe you can return to an old pastime. I enjoyed birds as a child and picked up the hobby years later.

- 4 Consider giving back – We have learned a lot about cancer during our journey. Those just starting out could benefit from our experience. Helping others can be very rewarding.

Being in remission is a real blessing. We should strive to make each day special.

## Section Five: When Recovery Isn't Possible

Mortality rates for cancer have dropped significantly. Sadly, it still claims many victims. Chapter Fifteen discusses handling terminal cancer. Chapter Sixteen is for loved ones.

## Chapter Fifteen: Facing Death

There are some people you will always remember even if you met them just once. Charlie was one such person. He played and coached in major college football but was confined to a wheelchair. He was dying of cancer. In spirit, he had changed little from his gridiron days. He was very animated as he talked. It was clear he was going to savor every bit of life he had left. Looking at him reminded me of Karen and her indomitable spirit. He died just a couple of weeks later.

We cannot escape the fact that we are mortal beings. None of us is guaranteed another heartbeat. We usually see death as something happening so far in the future that we don't need to think about it. Cancer can sometimes force us to face the ugly truth that we are going to die.

Many are willing to discuss intimate details of their lives. Death seems to be the last taboo. People are uncomfortable talking about it. With some, the fear is so great that they avoid those with a terminal illness. We need to bring it out of the shadows and discuss it openly and honestly.

Some will have to decide whether or not to continue treatment. Then it's a matter of coming to terms with the diagnosis, putting your affairs in order and managing your health. Once this is done, you can focus on leading as satisfying a life as possible, just like Charlie.

I know what it is like to have cancer and to lose someone to it. Perhaps I won't survive when my cancer returns. Of course, there is a huge difference between imagining what it might be like and experiencing it firsthand. I've given this chapter a great deal of thought and research and hope you find it useful.

## Making the Decision about Ending Treatment

The ultimate outcome is never in our power. All we can control is how we respond. Stopping treatment does not mean giving up. Instead of a fight for quantity of life, it is a fight for quality of life.

Here are some thoughts:

### **Make sure you have all the information**

A person must have the facts to make an informed decision. If time permits, a second opinion might be useful. In Shakespeare's *Romeo and Juliet*, not having the right information caused both lead characters to commit suicide.

### **Make the decision based on facts, not emotions**

Feelings are fleeting so we can't allow them to impact the decision. Some act out of desperation and spend their last months of life chasing after questionable cures. Unfortunately, there are those who prey on people's fears. As hard as it is, we must face facts instead of giving into fear.

## **Take time to think clearly**

General Patton said “Fatigue makes cowards of us all”. One really bad day shouldn’t be the basis for making the decision.

## **Commit to your decision**

Assuming that you have taken the time and effort to make a well thought out decision, commit to it. Sometimes a change in health may require making a new decision. My aunt had such an adverse reaction to her first chemo session that any more would likely have killed her.

## **Ask people to support your choice**

Some may not be ready if you choose to discontinue treatment. There is nothing wrong with getting their input but this has to be your decision and yours alone. Ask for their blessing even if they disagree. They may be acting out of the best motives but it’s not fair to ask someone to suffer for their benefit.

## **Coming to Terms with Your Emotions**

There are two very good reasons to accept your situation as quickly as you can. It maximizes time spent leading a life of fulfillment. It also allows you to help those around you who are still struggling.

I believe the process laid out in Chapter Four can be useful. Here are a few additional thoughts:

## **Feel your emotions**

Denial slows down the time it takes to accept the situation. The key is to feel your emotions without getting bogged down in self-pity.

## **Learn about death**

The more we know about something, the less frightening it is. Talk to a medical professional about what to expect.

## **Reflect on your life**

Take time to think about your life. Focus on happy times. We all have regrets but shouldn't dwell on them. We are imperfect human beings trying to do the best we can.

## **Find someone with whom you can share your feelings**

People around you may still be struggling with their emotions. If they can be open, you can help each other. If they aren't ready, try to find someone else. Sometimes all it takes is a person to listen. Don't hesitate to get therapy if you think it will help.

## **Find comfort in your spiritual beliefs**

Life after death is a common theme in a number of religions. This can be quite reassuring. Talking about your beliefs can be beneficial. You may want to contact a religious leader or others sharing your faith.

## **Avoid using euphemisms**

Some may use euphemisms. It's best to use words like death and dying.

## **Getting Your Affairs in Order**

Dealing with paperwork is likely the last thing on your mind. Getting your affairs in order is an act of love. Those you leave behind have enough to handle without managing a messy estate.

Here's what you will need:

### **A will**

Wills outline how property is distributed and minor children cared for. You may want to disinherit someone. If so, be careful. You don't want to be remembered for an act of bitterness. Some try to control things from the grave. This can make life more difficult for their heirs.

### **Power of attorney**

You name someone to represent you in financial and legal matters if you are unable to do so.

### **Living will**

A living will, also called an advance healthcare directive, allows you to specify the circumstances under which treatment is withdrawn.



## **Healthcare proxy**

It names the person you want to make healthcare decisions if you are unable to do so.

## **Important papers and information**

There should be a place for legal documents, insurance policies and other important papers. You should include information on bank or investment accounts, key passwords and anything else someone might need.

## **Funeral**

Making funeral arrangements right after losing a loved one can be a distressing experience. It can also result in thousands of dollars of unnecessary expense.

If possible, make them yourself. If not, be sure to express your desires. Specifying funeral and other final wishes in writing can prevent family discord and ensure they are carried out.

## **Disposition of Your Remains**

This is an emotional issue for everyone involved. Expressing your desire makes it easier for your loved ones. If you want to be buried, you need to decide where. If possible, purchase a cemetery plot.

Cremation is becoming more popular. A casket can be rented for the visitation and funeral. Specify what you would like to be done with your ashes.

## **Contact List**

Put together a list of people you would like to be notified at your passing.

## **Managing Your Health**

Teams of doctors, nurses and other health care professionals administer hospice care. Hospices allow people to die peacefully and with dignity.

Here are a few suggestions:

### **Make use of them**

Most insurance plans cover them. There are certain requirements to be eligible.

They supply equipment, specialty nursing, personal care aids, pastoral and counseling care for the patient and their family.

This is done at your home or at times at a health care facility or nursing home. Care may be provided at a hospice facility to assist with acute needs such as uncontrollable pain.

### **Speak up**

The medical professionals' sole focus is to make you as comfortable as possible. Let them know what is happening.

### **Keep informed**

There are still choices to be made. For example, a strong painkiller might make you woozy.

## The People in Your Life

They have been given devastating news and are trying to cope just as your needs from them have increased. As challenging as it is, this can be a special time to bring people closer.

### **Your physical needs**

Your medical status dictates the type of physical assistance that is necessary. It could be anywhere from someone to run errands to having a caregiver.

### **Your emotional needs**

It can be a time of incredible closeness. I once visited an acquaintance who was dying of cancer. That family showed more love and joy in being together in an hour than many families do in a month.

There are many ways those around you can offer their support both on good days and bad. Any contact at all, even if it is electronic, can mean a lot. Just being with a person can be comforting.

Don't be afraid to ask for support. You can't expect a casual acquaintance to fly across the country or visit you every day. Make sure to show your appreciation but don't overdo it. There will be tough days when you want to vent. Just make sure you don't do it all the time or aim it at your visitors.

This is a time for deep, meaningful conversations like we saw in the book and movie *Tuesdays with Morrie*.

## **Healing a rift**

Relationships are difficult and sometimes things go asunder. Whether or not you try to heal it is up to you.

## **Contact people**

Take some time to think about people you would like to get in touch with. Perhaps there are some you haven't heard from in decades.

## **Leaving a remembrance**

One day I found three voicemails from Karen. I really treasure them. Take the time to record a message or write about what they have meant to you.

Your family may also value written or oral memories of your life and genealogical information. It gives you a chance to answer their questions.

Designating a special object from you can mean a lot, especially to children.

## **Their emotional needs**

There are a number of ways you can support them. The most important is to not take out your anger on them. Allow them to be themselves and talk openly and honestly with you. Try to relate to them as family or friends. That will make it easier for you to respond as yourself rather than as a cancer patient.

## **Limiting visitors**

At some point it may be necessary to limit your visitors. This allows you to save your strength for those closest to you.

## **Having a Meaningful Life**

There is no way to appreciate how special life is until a person is faced with death. Try to make each day worthwhile.

## **Life goals**

You may have life goals that might not be reached. Accept it and make new ones. They may even give you a little more time. One of the great coincidences of history is that both John Adams and Thomas Jefferson died on the fiftieth anniversary of the Declaration of Independence. Perhaps each man willed himself to live to that day. It is unimportant whether or not there is time to complete the new goals. The aim is to lead as rich a life as possible.

## **Make each day count**

Although I can't understand what you are going through, I was an eyewitness to Karen's experience. She certainly had some tough times but was upbeat much of the time. She even laughed at a joke on the day she died.

We spend a lot of time doing things because we are "supposed" to do them. Most of us spend too much time on unimportant things. Focus on whatever is most

important to you. Perhaps you don't have any special goals. That's fine. Spend your time doing what you love. Try to find a way to make each day count.

Pursue things you have enjoyed even if you have to modify how you do it. If you are a birder like me, you still can watch them come to a feeder.

This will be a difficult time for you and your loved ones. My hope is you are able to make the most out of time you have left.

## Chapter Sixteen: Saying Goodbye and Moving On

People experience loss in many ways. Karen's death was very difficult for me. My dad died at age 101. Rather than mourning his loss, I felt grateful to have had him in my life for so long.

To me, there was a difference between accepting her death and coming to terms with my grief. I accepted that she was gone the day after she died. It would have been selfish for me to want her suffering to continue.

At first, I focused on just getting through the day. Even on a good day, life seemed pretty pointless.

Friends and family were supportive. They hadn't been through something like this and didn't know how to help. My dad suggested that I don't think about it. That's a lot easier said than done. I contacted an old friend I hadn't seen in years. Her husband died the previous year. Talking to her really helped.

I took my usual math geek approach and read a number of books on grieving. They were of varying quality.

After two years I decided I wanted to begin dating. I knew I had to resolve my feelings first. I bought the book *Mars and Venus: Moving On*. The first section dealt with recovery. It discusses emotions that we need to experience in order to heal. I wasn't sure if it would work but it did.

Even though I have come to terms with losing her, I still have difficult moments. I went out to eat with some friends. We went to the same restaurant we were at after her funeral. I love the place but will never go back.

Many face a much greater challenge than I had. Some, including Karen, had to earn a living and raise a family without their spouse. I can't imagine anything worse than losing a child.

The ultimate goal is to build a meaningful life for ourselves. Working through grief is a big part of it but that alone won't give us a life of fulfillment. I believe there are six phases that we move through. They are the initial period, saying goodbye, coping with loss, getting back on track, going through the healing process and building a meaningful life. For those who lost a partner, there may be a seventh phase, dating.

## The Initial Period

Nothing can prepare us for the news that someone we love is going to die. We are shocked and scared. For some, the reaction is so strong that they can think of little else. They are paralyzed by fear.

However, time is precious. We are just trying to reach a point where we can function. Until we do, we can't make the most of the time we have together with them.

Like the initial period after diagnosis, we are trying to adjust to the news. I would suggest that you reread Chapter Four. There are no magic fixes. Getting



through this phase allows us to focus more on the patient and our relationship with them.

## **Saying Goodbye**

This is a challenging time. Our hope for a future with our loved one is gone. We have to stand by helplessly and watch them suffer and decline.

As hard as this time is, having time with them is a blessing. Many lose loved ones suddenly.

Nothing will make the pain go away. Instead of dwelling on it, we need to try to make this time as special as possible. As bad as it was, I have some very wonderful memories from that time. Here are some ideas that might help.

## **Make it about them**

We may feel like we are losing a part of ourselves. However, they are losing everything. We should focus on doing what we can for them. It may help ease our pain. It may also bring us closer. This means we have to support their decision to end treatment.

## **Take things a day at a time**

One of the most important ideas in this book is that we have to focus on today. This is particularly important when time with our loved one is limited.

## **There is no right way to feel**

Thinking that we need to feel a certain way puts unnecessary pressure on us. As long as our feelings aren't harmful to us or others, it's OK to feel any way we want.

## **Try to avoid anticipatory grieving**

Some think they need to prepare for the loss. Based on my experience, I think there is little we can do. We need to focus on the time before death, not after. Grieving for someone who is still here doesn't help anyone.

## **Don't rehash the past**

Some people focus on playing the what if game. They imagine scenarios in which things might have been different. The future has unlimited alternatives while the past has none. We need to stay in the present.

## **Don't focus on life expectancy**

As discussed in Chapter Eight, don't focus on how much time they may have left unless it is near the end. It takes our attention away from making the most of our time together. Having a good day with them is special no matter how much time they may have.

## **Don't expect others to understand**

Depending on your age, it is possible that few, if any of your acquaintances have experienced this. We can't expect people to understand something they haven't been through. Talking to someone who has been there can really help.

## **Follow their lead**

In relationships, we often treat people the way we want to be treated. I remember when an extrovert wife threw her introvert husband a big surprise birthday party. He would have preferred a quiet dinner with a few close friends.

We can best serve our loved one by following their lead. Good communication is essential to understanding how we can help them.

## **Help them achieve life goals**

For some, working toward a life goal can help give their life meaning. Do what you can to help them.

## **Explain how you benefit by helping them**

Some cancer patients don't want to be a burden. They may be more willing to accept help if you tell them that it lets you feel useful.

## **Have short, frequent visits**

They are less likely to get tired with a short visit. More frequent visits increase the chance of catching them on a good day.

## **Go with the flow**

One day I was telling Karen about a trip I had taken. She was very alert and asking questions. On the next visit, she knew nothing about it.

Going through confusion shakes a person's confidence. Correcting them just makes it worse. Try to go with the flow.

## Coping with Loss

It's hard to imagine a world they are not part of. All we can focus on is just trying to get through the day. Many have family and job responsibilities they must perform regardless of how they feel.

Sometimes cancer progresses very rapidly. This makes things more difficult for loved ones. However, it means the patient avoided a lot of suffering. As much as I treasured every moment with Karen, I would have gladly given up some time with her to spare her so much pain.

In this stage, all we are trying to do is get to the point where we can begin to resume a semblance of our regular life. Sadly, some people remain stuck in this phase. Here are some ideas that might help:

### **Don't beat yourself up if you weren't present at their death**

I wasn't there when Karen died. What is more important to me is that I was there when I could help her.

### **It's OK to be happy**

I attended the funeral of an aunt just a few weeks after Karen's death. There are some great storytellers in the family so I was laughing much of the time.

Some may think they aren't respecting their loved one if they have moments of happiness. I believe just the opposite is true. My aunt was a funny person who loved to laugh. I believe she would have heartily approved our happiness.

As I have already said, it's OK to feel the way you feel.

### **Watch out for post-funeral letdown**

There are lots of people around after someone dies. They go home after the funeral. Don't be afraid to ask for help.

Spending time with someone can ease the transition. I stayed with some close friends after Karen died.

### **Accept the grief**

Some may try to pretend they are OK. We can't recover if we are living in denial.

### **Try not to be strong for each other**

Just as with the patient and loved ones, being strong for each other may cut off communication. You can help each other by openly discussing your feelings.

### **They can still help us**

Our loved one is gone but they can still help us. I used the example of Karen's strength to inspire me. We knew them well enough to know how they would respond if they could communicate with us. Thinking about the life they hoped for us can encourage us.

Recently I saw a post from a man so distraught over losing his wife that he was considering suicide. I asked him what he would want for his wife if he was the one who died. I hoped that thinking about what she wants for him would keep him from taking such drastic action.

### **Grieve in your own way**

I loved Karen very deeply but never cried. I was feeling my feelings but crying just isn't part of my nature. We each need to grieve in our own way.

### **Talk to someone in your situation**

The nature of our grieving depends on the relationship we had. There is a big difference between losing a partner, parent, sibling, child, close friend, etc. It is beneficial to talk to someone who has had the same type of loss.

### **Write about your loved one**

My dad was a very interesting person. To help preserve his memory, I have written down over 120 stories about him.

You might want to write about your loved one. It brings back happy memories and can help the recovery process.

### **Postpone major decisions**

None of us should make major decisions at a time when we are so vulnerable.

## **Force yourself to take action**

After my grandfather died, my grandmother only left the house when it was absolutely necessary. I suggested we visit my aunt. That helped her to get going again.

Do something that was once enjoyable even if you don't feel like it. The object isn't to have fun but to help us move to the next phase.

## **Getting Back on Track**

It takes a long time to come to terms with losing someone close. I believe that most of us need to get back on track before we can become healed. For some, that means starting to build a new life.

The emphasis needs to be on action, not feelings. Taking action, regardless of how we feel, is a victory in and of itself.

## **Find inspiration**

I wanted to totally ignore Christmas the year Karen died. On a visit to a grocery store, I heard some small girls singing Christmas carols. That totally changed my attitude.

We can never tell what might inspire us. That's why we need to pay attention to what's going on around us.

## **Get out of the house**

Being retired, it was easy for me to stay in the house. These days many people work from home. We need to get out even if it's just going for a short walk.

## **Be around people**

We may not feel like being around others. This is an important part of getting back on track.

## **Go out on your own**

It can be difficult to do things on our own. I know someone who never eats dinner out alone even though her husband died years ago. As hard as it is, we need to learn to be out in the world. If someone in a restaurant says “Just one?”, don’t let it bother you.

## **Work on your health**

We may not pay close enough attention to our health. Watching our diet and exercising may make us feel better about ourselves. Make sure any health problems are addressed.

## **Pursue your interests**

We may not feel like pursuing activities we once found pleasurable. Getting back to them is an important part of being back on track. Finding new interests would be great but may come later.

## **Help others in need**

Sometimes we may feel we are the only one with problems. Finding ways to help others lets us see we are not alone.



## Starting the Healing Process

We can think of our grief as a dense jungle. There are three choices we can make. We can pretend it doesn't exist. The problem with buried emotions is that they can resurface, often as health issues.

Others may choose to stay in the jungle. A friend attended a support group. A few of the women were wailing and carrying on over husbands who had been dead for many years. That may get them attention and sympathy but it's not a good way to live.

A much better approach is to find our way out of the jungle. It's not easy. The path has many twists and turns. We may think we are out of it but it's just a clearing. If we keep at it, we will eventually leave the jungle.

We each need to find our own path but there are some "rules of the road" that can help us.

### **We need to move at our own pace**

I know a guy who began a relationship three months after losing his wife. It has worked out well for him. Most of us will need more time. The important thing is that we keep moving through the jungle.

### **We need to come to terms with it, not get over it**

Sometimes people say we should get over it. I think that is unrealistic. I will miss Karen every day for the rest of

my life. However, I have found my way out of the jungle. That's what we need to aim for.

### **We need to feel our emotions without wallowing in them**

We can't come to terms with our loss without experiencing our feelings. We just need to make sure we aren't overcome by them.

### **Guilt, self-pity and jealousy impede our recovery**

Losing someone close can bring on feelings of guilt. I see posts from people who think they should have been able to save their loved one. We often assume we have special powers to change things. We need to understand what we can and cannot control.

We all have things we wish we would have done differently. There is nothing we can do to change the past so there is no point dwelling on it.

I previously mentioned survivor's guilt. As I said before, we shouldn't feel guilty about something beyond our control.

Self-pity can impede our recovery. It is understandable that we may feel that way but it keeps us stuck in the jungle.

Sometimes it is hard to see others enjoying their loved one when ours is gone. Being jealous of them can hinder our progress.

## **Use the memory of loved ones inspiration**

Even though they are gone, they can still inspire us. The example of Karen's strength has helped me face some difficult challenges. Knowing that she wants me to be happy has made a huge difference. Your loved one wants the same for you. They can no longer comfort us but memories of them can.

## **We cannot predict how we are going to feel**

I made a number of plans for the first anniversary of Karen's death but didn't leave the house. I was prepared for a really rough day on one of her birthdays. Instead, it was a wonderful day full of memories of our time together.

We may think we are handling things well and fall apart the next day. That's perfectly normal. Those feelings will pass.

## **We may experience past feelings of loss**

What we are going through now may bring up memories of past losses. We need to deal with those feelings as well.

## **Don't do this alone**

Grieving is certainly a difficult experience. We should not try to do it alone. Family and friends can give us support even if they don't understand what we are going through. Those who have been there can be a big help. Earlier I mentioned the friend who helped me so

much. We can also get help from social media cancer groups.

If you think it would be of benefit, give counseling a try. You may wish to consider joining a support group.

### **We will have painful moments even after we have healed**

Just like my experience in the restaurant, there will always be difficult moments. Writing this chapter has produced some for me. We need to accept them but not be overwhelmed by them.

Nobody can tell you how to make it through the jungle. We each need to find our own way.

### **Building a Meaningful Life**

My focus here is on the loss of a partner. It requires the most change and that's where my experience has been.

We can begin building the life we want while still in the jungle. Making changes is likely easier after we have healed.

Knowing that they want us to be happy should help. I feel we honor them by leading the kind of life they would hope for us.

This will be a work in progress. We should continue to find new ways to improve our life. Here are a few ideas that might help.

## **Make your own way**

Our thoughts about the future were of us as a couple, not a single. We may be tempted to follow through on plans we had but need to make our own way. I knew a couple that was nearing retirement and planned to move to another state. After the husband died, the wife went ahead with the move but eventually moved back.

## **Meet new people**

Losing a partner may mean changes in relationships. Some couples friends may disappear from our life. Even if it doesn't happen, we should try to expand our circle of acquaintances. Start with organizations you are already involved with and go from there.

## **Find new interests**

We need to find new interests. Ideally, some of them will get us out of the house meeting new people.

## **Redecorate**

Many are tempted to leave their home just as it was. That made sense during healing but now it's time to make it your place.

## **Enjoy your new life**

This is a time when we should be open to new possibilities. It was when I discovered how important helping patients and loved ones was to me.

Some changes may not work out. That's not a problem. If we keep trying new things, we will create a life we are well suited for. Make sure to enjoy your new life.

## Dating

Some people don't have an interest in dating. This is especially true of older people who were with their partner for a long time. That decision is perfectly acceptable. It should be a positive lifestyle choice, not one made out of fear or guilt.

There are many books out there on dating. I already mentioned *Mars and Venus: Starting Over* which I highly recommend.

Here are a few guidelines you may want to follow:

### **Make sure you are ready**

Before I met Karen, I went out with another woman for a while. She had been divorced for ten years but was not ready to move on. I don't think she will ever get there.

We need to make sure we are ready. That means that we have come to terms with our loss and are open to the possibility of finding love again.

### **We are the only ones that can fix our lives**

Some may feel their life would be great if they could find a partner. We are much less likely to do so if we are still recovering. We need to fix ourselves first.

## **Don't look for a replacement**

Karen was one of a kind. I am sure you feel the same way about your partner. While we may want a person with some of their qualities, we shouldn't try to find someone just like them.

## **Know what you are looking for**

Some may want a serious relationship while others may want to be more casual. If there are still minor children at home, that needs to be a consideration. We have to know what we are looking for.

We also need to have some idea of the type of person we want (or don't want). These are general guidelines. Some fall in love with people they never imagined being with.

## **Take your time**

Getting back into the dating world is exciting (and a little scary). We need to take the time to find the right person. We shouldn't fall in love with falling in love. I remember someone telling me how excited he was about a woman he met. Not long after that he met his future wife.

## **Focus on what is important**

When I was doing online dating, I noticed that some women had the same criteria they had when they were teens. We should focus on what is important to us now.

## **Make sure they are comfortable in your home**

It certainly isn't necessary to eliminate all reminders of your late partner. However, make sure that your home isn't a shrine to them.

## **Family**

Deciding to begin dating can be hard on family members, especially children. They may think we are trying to replace our partner. They don't understand that we will always love them. All we want is to find some of the happiness we once had.

Dealing with loss is a long painful process. I hope that your journey leads you to a life of happiness and meaning.



## Some Final Thoughts

My experiences with cancer have given me a strong desire to help other cancer patients and those close to them. That, plus my enjoyment of writing, has made this project a labor of love.

I would enjoy hearing from you. My email address is [davidreichlinger@gmail.com](mailto:davidreichlinger@gmail.com) . It would be nice to hear if you liked the book. I especially want any suggestions on how it can be improved.

My wish for you is symbolized on the cover: victory followed by blue skies ahead.

Normally the conversation between author and reader is a one-way street. If you think talking to me would be helpful, I'm sure it could be arranged.

**KEEP FIGHTING!!!!**